



Lymphatic Education  
& Research Network

# AN AMERICAN TRAGEDY

## Neglected Lymphatic Diseases



**An Appeal to Congress  
to Establish a National Commission  
on Lymphatic Disease Research**

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**Lymphatic Education & Research Network (LE&RN)** is an internationally recognized nonprofit organization founded in 1998 to fight lymphatic diseases, which include lymphedema and lipedema, through education, research and advocacy. LE&RN seeks to accelerate the prevention, treatment and cure of lymphatic diseases while bringing patients and medical professionals together to address the unmet needs surrounding these diseases. [www.LymphaticNetwork.org](http://www.LymphaticNetwork.org)

#### **Photographs by John Noltner**

John Noltner is an award-winning photographer and founder of *A Peace of My Mind*, a multimedia arts project that uses portraits and personal stories to bridge divides and encourage dialogue around important issues.

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## A Call to Action for America's Leaders

Up to ten million American men, women, and children live with the progressive, debilitating, and incurable lymphatic disease (LD) called lymphedema (LE). Another estimated seventeen-million women suffer from the lymphatic disease lipedema. Tens of thousands of children are born with lymphatic malformations, resulting in physical abnormalities that can shorten lives. There are no cures. There are no approved drugs. Treatments that do exist are often not covered by insurance. *It is time for this to change.*

In addition, there is a continuum of diseases impacted by our lymphatic system. These include heart disease, diabetes, rheumatoid arthritis, AIDS, and obesity. Recent groundbreaking research has shown that malfunctioning lymphatic vessels in the brain also play a role in Alzheimer's disease and Multiple Sclerosis.

Yet, annual lymphatic research funding at the National Institutes of Health (NIH) hovers around \$25 million, with only five million dollars of this dedicated to clinical lymphedema research. Whereas the Centers for Disease Control and Prevention (CDC) expends considerable resources fighting the mosquito-borne disease of lymphatic filariasis, which is not even found in the United States, considerably less attention is given to other lymphatic diseases, such as lymphedema and lipedema. And although a research study states that American medical schools *spend as little as 30 minutes on the lymphatic system during a doctor's education*, the American Medical Association (AMA) has been silent on this issue.

The only way to end this American tragedy is for those in power to boldly act.

- We ask that NIH establish a **National Commission on Lymphatic Disease Research**, as was called for in the *2019 LSSH Appropriations Bill*.
- We seek inclusion of "*lymphatic diseases*" as conditions eligible for study within the Department of Defense's **Peer-Reviewed Medical Research Program (PRMRP)**.
- We call on the CDC to institute an education campaign and research grants on all lymphatic diseases, including lymphedema and lipedema.
- We ask the **American Medical Association** to use its voice to secure the expansion of lymphatic study in medical school curricula so we can move beyond the status quo where medical practitioners misdiagnose or mistreat these diseases.
- And we call for Congress to pass the **Lymphedema Treatment Act** to provide Medicare coverage for medically necessary treatments.

In the pages of this booklet, you will meet over two hundred champions who live with lymphatic disease and are setting a course for change. *We ask you to join them.*

Sincerely,

William Repicci  
LE&RN President & CEO

Kathy Bates  
National Spokesperson



***“I started experiencing swelling of my leg after inguinal hernia surgery. I was misdiagnosed and not properly educated on how serious or life-altering having lymphedema would be.”***

**KIMBERLY GLOVER**  
Washington, DC

## **DEE GRIDER** Huntsville, AL

Seven years ago I developed lymphedema after a double mastectomy and lymph node removal surgery. I am blessed to have a very experienced therapist in Huntsville, Karin Hislop of Therapy Achievements. She helped me get my disease under control through manual decompression massage. But I needed more help to be able to take charge of this incurable condition.

I use custom compression garments and a pneumatic compression pump. Fortunately, my insurance covers these items but not without a fight every time I replace my garments biannually. Many of my friends are not so blessed and can not afford to purchase these items. **Please make therapy, compression garments and devices covered by insurance and Medicare.** These care items are necessary to control swelling and prevent serious infections. Lymphedema deserves more research and funding to help the millions of us who suffer with it.

## **LAURA ODEN** Anchorage, AK

I have struggled with lymphedema my whole adult life. Like many others, surgery stopped the cancer but also started a lifelong struggle with chronic swelling in my right leg and foot.

I lived my lymphedema life in isolation, unaware of the millions of others who shared my struggle. **My doctors had little or nothing to offer me.** They became a repetitive chorus of “I don’t know what to tell you”.

In 1998 I had an emergency C-section to a preemie, and was introduced to treatment. After that, I had lymph node transfer surgery in 2014. I am religious about compression stockings. Eventually, I learned about online support groups. I learned that I was not alone.

Once I broke free of my isolation, I found myself intensely motivated to do something to make our lives better. This is when we—myself and two co-founders—started a shoe company to make shoes to accommodate edema. Because of this, I talk with lymphies every day. **There are so many others suffering because they don’t have the right support or treatment.** Good treatment is indeed the secret to health and happiness for everyone like me that has this chronic condition.

## **AMANDA HADAWAY** Surprise, AZ

I was diagnosed with lipedema in May 2019. I also have lymphedema, so I actually have lipolymphedema. These diseases cause me daily pain and they have limited my mobility quite a bit over the last 10 years. Unfortunately there is not much knowledge, even among the medical community about lipedema. It’s very hard to get diagnosed and to get the care you need. Our conditions aren’t covered by insurance. These are lifelong diseases that affect our quality of life. **We need education, awareness, understanding and insurance coverage.**

## MARIA HOOVER

### Flagstaff, AZ

From very young I was told I was “meaty”. Kids made fun of my big arms and I thought I was muscular. Even though I was outside riding my bike and swimming, I couldn’t lose weight. I began dieting at 12! I began menstruating at 9 and had terrible painful periods. I struggled through, never gave up, and after college I was a Principal at 26! I was brave, confident, and achievement oriented. I was even a body builder in my 20’s! At 30 the weight began to be out of control. I tried every diet, even starvation! I’d lose 15 or 20 pounds and gain that back and more. My self-esteem plummeted and as my body grew, so did the fatigue and pain. Periods were the worst! At 42 the cysts were so large I had to have a hysterectomy and gained 80 pounds!

I went on a prescription diet and lost 100 pounds eating 800 calories a day, swimming laps 3 hours a week, and riding my bike seven miles, three times a week. Sadly, once I added food back, I gained back 60 pounds! **My self-esteem was gone. The accomplished woman I had been in my youth was gone.** I could barely walk from DDD and hip problems. I couldn’t sleep due to pain. I was told to lose weight and eat well when I barely ate! I learned I had lipedema! I bought a swim spa and had liposuction paid by inheritance. Now I eat very little (low carb), fast, and burn 3500 calories a week in the pool. My life is only about this disease at 62. But no more pain.

## DANA HUCK

### Scottsdale, AZ

Diagnosed in 2018 at age 34 after a single lymph node removed for a melanoma diagnosis. **Lymphedema rules my life: my comfort, my confidence, my ability to get up and go.** The 24/7 compression is a daily reminder of cancer and what I have lost. I have two young kids and want to do everything in my power to stop lymphedema progression so I can be the mom I want to be for them.

## IRENE WESTWOOD

### Phoenix, AZ

I was 35 years old, had two small kids, and had just started working as a teacher in elementary school, when I was diagnosed with cancer. After treatment I ended up with lymphedema in my left leg and it felt like a slap in the face. **I can no longer work full time as a teacher, my level of activity is much lower than before and I have to rest several times through the day.** Though I am cancer free, I am reminded of what it did to my body and my life every day for the rest of my life.

## RONALD AFDAL

### Concord, CA

My four-year-old great grandson has experienced lymphedema since birth, causing swollen hands, feet and legs. This necessitates the constant wearing of compression clothing to minimize swelling and form some protection from injury and infection to the swollen

areas. **Research funding for treatment and hopefully a cure would benefit the many needing relief from this illness. I hope Congress will give a top priority for this.**

## NICOLE AWETI

### Oakland, CA

I was diagnosed with primary lymphedema at age 11. My doctors said there was no treatment, and it might get worse. I didn’t receive treatment until I was 23 years old when I did my own research to find an occupational therapist who specialized in lymphedema. The treatment helped, but if it had been treated and managed from the onset, my life and left leg would have been much different. Instead, I endured physical pain and discomfort, as well as social stigma during my adolescence.

My lymphedema is under control now, but I am only 32 years old. I worry about my health and mobility in the future. **I worry about the cost of compression garments, pumps, and night time garments that I need to manage my swelling.** A cure would give me hope for a healthy future and ease my anxiety about cost of equipment and arguing with insurance companies. A cure would also decrease my worry about the possibility of my son or future children inheriting lymphedema from me.

## EMILIE BECK

### Los Angeles, CA

I developed lymphedema in my right leg almost two years after surgery for ovarian cancer. **I wasn’t warned of it, nor was it taken seriously by my surgeon.** I did my own research and insisted on seeing a lymph PT who confirmed it. I’d love to find the “gold standard” of CDT, but it’s cost-prohibitive, even with excellent insurance. So I keep my lymphedema “managed” like a part-time job: exercising, wearing compression, bandaging, pumping, massaging every day, over and over again, just to keep it from progressing.

My world, my life, has become much smaller. The heaviness in my leg has become an overall emotional heaviness. A cure—or even appropriate treatment—would bring back joy, hope, and possibility. **Please, please, take this condition seriously. The medical community should be as educated as every patient has to be in order to endure. And lymphies shouldn’t have to suffer from lack of treatment in the wealthiest nation.**

## LINDSAY BENNETT

### San Diego, CA

My name is Lindsay Bennett, and I am 28-year-old female who loves sports and being active. I grew up playing sports. I played soccer, softball, tennis, basketball, lacrosse, football, rugby, and field hockey. You name it, I was trying it. I fell in love with field hockey when I started playing in high school and got a Division 1 scholarship to play at Northeastern University. My dreams had come true until they were later shattered. I was diagnosed with lymphedema at the age of 23. Needless to say, my life will never be the same.

This disease destroys me physically and emotionally. Every morning I wake up with a big black night garment on and am reminded that I’m not normal. Taking care of my lymphedema is a 24-hour-a-day



***“My world, my life, has become much smaller. The heaviness in my leg has become an overall emotional heaviness. A cure—or even appropriate treatment—would bring back joy, hope, and possibility. Please, please, take this condition seriously.”***

**—Emilie Beck, Los Angeles, CA**

job. It's a constant worry how my leg feels, how my leg looks, and how my leg will handle the day-to-day activities.

**A cure for lymphedema would make me whole again. It would allow me to not plan my every move and just live my life. It would propel me to fulfill my career dreams and be a normal 28-year-old female again. A cure for lymphedema would change my life forever.**

## **JACQUELINE BROCK** **Indio, CA**

I was 40 years old, undiagnosed for 5 years, Stage 3 BC, 12-year survivor. I saved my own life because I believed the diagnostics were incorrect in my diagnosis. Five mammograms, 3 ultrasounds all NORMAL, until an ultrasound completed by a Radiologist at my request recorded the findings of cancer. I had a lumpectomy and 18 lymph nodes removed in surgery in 2008. **I have suffered more from the lymphedema and the cellulitis infections in my arm, than I ever did from chemotherapy.**

I am only 52, and it has been a blessing to be alive and see all the miracles and milestones with my beautiful family. However, the physical setbacks, fevers, infections and value of life has been severely challenging for the entire 12 years. **Only four of 18 lymph nodes were positive for cancer. Yet the other 14 healthy lymph nodes were surgically removed because my surgeon “knew best.” This is my journey!**

## **KENNETH BRUNSKILL** **Fremont, CA**

My late nephew's oldest daughter (my grand niece) has a son (my great grand nephew) who was born with and has acute lymphedema. I am the youngest and only living son of the Brunskill (paternal) side of the family, making me the family patriarch. To my knowledge there is not any family history of lymphedema or any form of it, on either my father's or mother's side of the family. This condition has us all very concerned, particularly amid this Covid-19 pandemic. Our great grand nephew is 3+ now, and an active young man with a wonderful happy life. He is so very fortunate to have such wonderful caring parents, and a Nurse Practitioner grandmother.

However given all the loving and professional care he has, it pales in comparison of what could be done for him and the many others

with the same condition. **This needs the full weight and power that Congress can provide through funding more directed research for therapeutics, and cures for this condition.**

## **SARAH BRUNSKILL** **Pleasanton, CA**

Immediately after my son Grayson was born (August 2016), the delivery pediatrician was concerned with the atypical full body swelling (later diagnosed as congenital lymphedema) and sent him to the NICU for observation. We were in the hospital for five days for monitoring, running labs, tests, and genetic tests to try and understand what was happening. **No one could find a cause. Which is where we still are today, in medical limbo and blind to any complications that could come down the road. A parent's worst nightmare.**

Currently Grayson's lymphedema is managed by custom daytime and nighttime compression garments. These garments have to be specially made for him in different parts of the world as there are no off-shelf garments for children. Additionally, these garments need to be replaced every 3–4 months to accommodate his rapid typical growth that is typical for young children. **This has led to a huge financial burden on our family as one full set of daytime garments can cost up to \$4000 and a nighttime set up to \$5000. To date, insurance fights us every step of the way and, at times, denies these medically necessary treatments.**

## **JUDY BURROWS** **Huntington Beach, CA**

I developed lymphedema shortly after removal of all the inguinal lymph nodes in my left leg due to metastatic melanoma. I'm thrilled to be a nearly 20 year survivor of the cancer, but lymphedema is a burden and constant reminder of the disease. My left foot, leg and abdomen are about 20% larger than my right. It has impacted my appearance, self image, health, marriage and many of the athletic activities I used to enjoy. Getting approval for massage therapy, compression garments, and a compression device is a frequent challenge. **Even though there have been surgical solutions for several years, my insurance continues to consider it experimental.** Even with diligent care, I have suffered cellulitis.

People who suffer this disfiguring and life shortening disease deserve more dollars to go to research for a cure.

## SUE DECOITE Beckwourth, CA

Surviving breast cancer, mastectomy with reconstruction and radiation treatments, lymphedema was the icing on the cake. Even though I'm a cancer survivor, lymphedema is a daily reminder of that fight. In other words, there isn't a day that I don't think about cancer. Daily massage, compression sleeve, nightly Flexitouch Pump usage, physical therapy support with laser treatments...How could I forget about my fight with cancer? Even getting dressed every day, trying to find something to wear that will fit over my enlarged arm is frustrating. My closet is full of clothes that I can no longer wear or feel comfortable in. Wearing a compression sleeve always conjures up questions from strangers and even family members. It becomes a conversation that I don't want to be having on a daily basis. This doesn't seem like much, but it becomes mentally draining on one's spirit. Supporting researchers to find a cure is so important to the wellbeing of cancer survivors. **I beat cancer, help me beat lymphedema!**

## SHELLEY DENYER Fremont, CA

In 2000 I went into the hospital for a regular total abdominal hysterectomy with bilateral salpingo-oophorectomy. The surgery was complicated by cervical cancer with bladder metastasis. After eight weeks of chemo and radiation I was diagnosed with adenocarcinoma, Stage 4. I started the fight for my life. I was 45 years old, married and with three children.

September 2000: My surgery involved removing the bladder and creating a pseudo bladder formed from my small bowel. Part of the surgery involved creating a temporary ileostomy and vaginal reconstruction.

September 2003: I returned to work as a home health nurse.

2003–2005: I started developing left leg edema and having episodes of cellulitis. Consequently, multiple tests, diuretics prescribed, and incorrect diagnoses.

September 2005: A diagnosis of lymphedema.

2005–2020: Lymphedema therapy, financial costs for compression therapy, time consuming self care and frustration trying to have a normal healthy life; re: finding shoes to fit.

**2019–2020: Candidate for lymph node transplant with liposuction. Insurance denied it because they said it was for cosmetic reasons!**

2020: Second consult for lymph node transfer, with no post compressions, and a doctor who would support my cause. Insurance approved. Surgery canceled due to Covid-19. Surgery date pending.

## KATIE DUNPHY Albany, CA

My friend's son was born with lymphedema and over the past few years I've seen firsthand the impact the diagnosis has had on their lives. He is an incredible kid, but his condition has a significant impact on his toddler life. Beyond that, his condition has been stressful for his parents, particularly just after his birth when they



***"I have been managing this chronic disease since I was 11 years old. Hear our cries to prioritize funds that are extremely needed to facilitate a cure!"***

**CAM AYALA  
Houston, TX**

were trying to understand the diagnosis and how they can best support him. **More research on lymphedema and treatments (and hopefully a cure) would greatly help not only my friends' family but other families in similar situations.**

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## LISA GAINSLEY Los Angeles, CA

37 years ago, when I was 13, my mother died from lung and brain cancer. This loss led me to a path of healing. My entire professional life I've studied the lymphatic system and its effect on disease. As a lymphedema therapist, I've worked with thousands of people who have lymphedema, or are at risk of developing it. The work is both rewarding and FRUSTRATING! **The treatment is akin to placing a band-aid on a proliferating inflammatory condition—the tools therapists are given to help their clients are archaic and insufficient—and not unilaterally covered by all insurance plans!**

My clients are often told by doctors that they can't find what's wrong with them. Surgeons don't inform them of the risks prior to treatment for which there's no cure! There are more warnings on Tylenol bottles and yet we still have to lobby Congress for funding for education and awareness!

**It's time to SHINE THE LIGHT ON THE PLIGHT OF LYMPHATIC DISEASE AND DYSFUNCTION. If we can cure AIDS, we can cure lymphedema!**

If you or your loved one faced a cancer diagnosis and the treatment led to a disfiguring disease, I know you would become our biggest ally. **Please don't wait for this disease to hit your own family. Act now, save lives, fund the cure, and be a hero!**

Lymphatic Health = Immune Health!

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## JAY GRANZOW Torrance, CA

Every person suffering from lymphedema or lipedema deserves the opportunity to regain physical mobility and health. **More funding for timely treatment, training, and care is essential.**

Lymphatic diseases are difficult and unique disorders that can be medically treated with proper early diagnosis, therapies and surgical intervention to stop the pain and suffering that I've seen so many patients have to experience.

**I implore you to support and fight alongside our lymphedema and lipedema warriors.**

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## KATHLEEN GRUBBS San Diego, CA

I was diagnosed with lymphedema after my 6th (ish) bout of cellulitis. I woke on the morning of my wedding with a fever and severe leg and lymph node pain and decided it was time to figure it out. I had experienced unexplained leg swelling off and on since my late teens and most doctors told me to ignore it, or attributed it to chronic ankle sprains from my years of college and professional basketball. One doctor told me I had CHF! I managed it in my 20s and 30s by running, swimming and exercise but periodically got knocked down by a severe infection. **Getting the proper diagnosis and treatment have been the key to my improved quality of life, health and mobility, but was only possible because I had access to a health care provider who finally listened and was willing to do the research.**

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## BARBARA HARMER Coronado, CA

I am a cervical cancer survivor of eight years. Shortly after surgery and treatment I developed lymphedema in my left leg. This is now a life long disease I am left to deal with. **Lymphedema is physically and emotionally debilitating. Everyday is a battle to stay healthy.** There is so much more to be done within the medical community to help the millions who suffer from lymphedema. Funds are desperately needed for finding a cure and helping find better therapies for patients. Education for doctors, nurses and therapists. **Please help us in fighting this disease so we all can live a better life.**

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## CHRIS HARMER Coronado, CA

My wife was diagnosed with cancer in 2011. After surgery, chemo, radiation, and treatments, in 2012 we found that my wife had lymphedema. We discovered this disease by Googling and trying to find out why one of her legs was swollen and retaining fluid. My wife is a survivor, and I thank God she is. It has changed our way of life, from exercise, diet, and physical activities. Insurance companies do not recognize this (for the most part) as a life-threatening disease. **There are millions that are affected with lymphedema. It amazes me how dangerous it is, and how poorly we seem to care about it.** We need to focus on the problem, acknowledge it, and make it a national cause to provide the very best care and treatment for people like my wife, and all of those affected. If you take the time to learn about this disease, the more you will understand how help and funding is needed. **You have a great opportunity to provide funding for those affected, training, and care givers. Please listen and help.**

***“There are millions that are affected with lymphedema. It amazes me how dangerous it is, and how poorly we seem to care for it.”***

**—Chris Harmer, Coronado, CA**



## KRISTIN HILLENBRAND

### Alpine, CA

Hi, my name is Kristin! When I was 24 years old I was diagnosed with stage 3 melanoma. I underwent two major surgeries to remove all cancerous lymph nodes, as well as a year of bio-therapy treatment. This left me with Stage 2 Lymphedema. Funding for this lifelong disease would greatly help my family in treating and maintaining my lymphedema!

**Between my lymphedema therapist, my lymphedema machine, my compression garments, and all of the other expenses that goes with this awful disease, it gets so expensive for my family and we struggle with the financial burden!** We have paid everything out of pocket and it has cost our family well over \$25,000. Please make this right so that insurance covers what we need for this lifelong disease! Thank you!

## KELLIE HOWARD

### Clayton, CA

One of the greatest and scariest days of our lives was August 16, 2016. The day my grandson Grayson was born. You see, he is our first (and only) grandchild and we were ecstatic on the day he was arriving!

His birth was a bit difficult for his mom so it turned out that he would come via C-section as he was presumed to be a VERY BIG boy. He was, but unfortunately it was not because he was pudgy baby heavy, it was because he was BORN with lymphedema! Why?? No one knows!! **Our little man now has a condition that will affect him the rest of his life and as of now there are no “cures”, no “treatments” and very little in the way of research being done.** PLEASE, PLEASE help our adorable Grayson to have the best life he can by giving more funding to find a way to help him and so many others in this situation.

## CHRISTINE LIEBER

### San Diego, CA

Facing life and death Uterine Cancer was rough! **But having to live with debilitating lymphedema for the rest of my life is unthinkable!** It's like playing a chess game, where whatever move you make throughout the day, you are constantly thinking how does it affect the limbs? Continuously fighting with insurance companies, going to MLD appointments, using pumps, garments, night garments, bandaging, infections, cellulitis. Emotionally and physically it's an exhausting existence! Yes, I am alive! But where is the quality? **So I ask you Congress—HELP!**

## KATHLEEN LISSON

### San Diego, CA

It is frustrating to me as a lymphedema therapist that this clinically curable disease is so undertreated. We need more insurance coverage for garments and ICG imaging and lymphatic microsurgery and super microsurgery.

## NATALIE MICELI

### Palo Alto, CA

After getting pushed around for years, six months ago I finally got diagnosed with primary lymphedema. It's an extremely limiting disease and the available therapy options are time consuming and limited. **Being a person under 30, development in this area would be life changing.**

## SYLVIA MONTERO

### Torrance, CA

It all started when I was entering puberty. I noticed that my legs were developing a lot of what I thought was cellulite. As the years went by my upper body always seemed normal size but my hips and legs were widening and becoming heavy. I was very active and didn't understand why I was fat. When I became a mother it got worse. I decided to talk to my primary doctor and she diagnosed me with lipedema at the age of 28. She said it was a rare fat disease. All those years of crying and not understanding why my legs were so big and painful all made sense. **I want insurance companies to understand that we need help and that surgeries and garments are a necessity for a better life to treat this debilitating disease.** My mother has this condition as well and she has lost a lot of her mobility at the young age of 53. So please, Congress, help us! Thank you.

## TERRY MOORE

### Sylmar, CA

**I have had symptoms of lymphedema in both legs for over 40 years, but was only just diagnosed in 2015.** Lymphedema causes me almost daily pain, often times so severe it makes it difficult to get around. There are no medications or treatments to relieve the pain, so I must try as best as I can to get through it until it eases on its own. I have learned that a delay in diagnosis happens to a lot of patients because of the lack of proper education of this condition by medical students and physicians and this was true in my case. Once I was diagnosed I found it extremely difficult to get the proper medical compression supplies that were needed to treat and manage my lymphedema.

**My Medicare insurance has not paid for any of my compression supplies, so I have to pay out of pocket, which is a large expense for most people, but even more so for individuals like myself who are living on social security disability (due to my condition).** In order to reduce or prolong the chances of the swelling in my legs getting worse, I must wear compression garments every day. Finding a cure for lymphedema would make it possible for me and all others with lymphedema to be able to live without the pain and full-time daily care involved with managing this disease. It would also relieve us from the high cost that puts many of us in financial hardships.



*"I've lived with this disease for 32 years. With every decision or choice I make in life, the very first thing I consider is the impact it will have on my leg."*

CATHERINE HOLLEY  
Quincy, MA

## JUAN REYES Sacramento, CA

Lymphedema is a serious chronic disease that plagues nearly 10 million Americans who are either born with the condition or who develop it as a result of trauma, surgical insult, radiation therapy, or a combination of these factors.

**In fact, the National Cancer Institute predicts a 42% increase in cancer survivors 65 years of age or older by 2020, and as many as 1.5 to 3 million Medicare beneficiaries who are cancer survivors will require treatment for their lymphedema.**

Timely diagnosis and treatment are often not available to patients, particularly those in rural areas, making lymphedema more difficult to manage with more negative health consequences due to delays in diagnosing and treating the condition.

## HELENE ROBERTS-KEPHART Coronado, CA

My dear friend was diagnosed with lymphedema shortly after battling cervical cancer. **I am shocked to learn what little research is done on lymphatic disease, much less taught to our doctors and nurses in their education process.** Education of this important cause is key. Please fund research for a cure for lymphatic disease.

## JENNIFER RODRIGUEZ Bakersfield, CA

I developed lymphedema as a result of having my lymph nodes removed after a surgical removal of a tumor. I have lymphedema in both legs. I struggle daily with pain and body image issues because of the way this disease has distorted my body. **In an effort to maintain this disease, I am only allotted two pairs (per YEAR) of compression garments. One to wear, one to wash. Do we expect the same of people's underwear?? This is ridiculous.** I pray for a cure but in the meantime, I pray people get what they need to maintain this condition. Maintenance of this disease will prevent hospital visits for cellulitis which will drive up medical costs. If left untreated, there is decreased mobility and functionality of the parts affected. I just want to live a normal and functional life as a contributing member of society. **We need your help now!**

## ALYSSA SEPULVEDA Modesto, CA

My experience with lymphedema is watching a sweet little boy conquer the obstacles he has been given at birth. He has swollen legs and hands, making learning basic motor skills difficult at times. More research is imperative to learn about what causes this disease and a cure for it.

## KAITLYN TANG

### Dublin, CA

My journey with lymphedema started shortly after birth when I was rushed to the hospital due to swelling of my hands and legs. But it took several years for doctors to diagnose me with lymphedema. Living with lymphedema is a daily challenge. I have protein-losing enteropathy and bilateral pleural effusions which cause frequent respiratory distress, infections and hospitalizations despite being on daily diuretics and regular albumin/IVIG infusions.

I miss a lot of classes at school. My feet and legs are too swollen to fit in most girl's shoes or pants. **My doctor says its like I'm walking with 20 pounds of weights all the time. Kids at school don't like to play with me because I can't jump as high and run as fast.** I'm so thankful to be under the care of many wonderful and compassionate doctors. After having numerous tests done including lymphangiogram, I was told my condition cannot be surgically fixed. I tried several potent drugs such as Octreotide and Sirolimus hoping to help with my severe swelling and frequent diarrhea, but nothing has worked so far. I'm participating in several Lymphatic studies and hope that soon there will be a cure for this lymphedema!

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## HANNAH TAYLOR

### RICHMOND, CA

I have been dealing with lymphedema since 2015, after my hysterectomy for uterine cancer. In spite of physical therapy and the use of compression garments, the condition has not improved. I also have a compromised immune system, because of myelodysplasia. A cure for lymphedema means that I may have another 10 years added to my life.

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## SUSAN TOGNOLINI

### Castro Valley, CA

Our great nephew Grayson was unexpectedly born with lymphedema three years ago. As any new parents do, my nephew and niece sought information, but not about feeding times, best toys, and sleep schedules. They needed to learn about lymphedema, so that they could raise Grayson with as few limitations as possible. This little guy is limitless in smiles, curiosity, intellect, and personality! **However, he is limited physically by the compression suit and gloves he wears every day. He will have health limitations. He will have some activity restrictions. That is why funding research is so important for him and for others who seek answers to overcome limitations.** Please fund research for the Lymphatic Education & Resource Network. It is important for families like ours seeking answers and seeking an informed future for our loved ones like Grayson.

## ELIZABETH VASQUEZ

### Pomona, CA

I have tried endless dieting, even a gastric sleeve. I have lost 70 pounds and yet my legs and arms look the same, while I cannot grab an inch of fat of my waist. I'm devastated that my legs will never look "normal" and now, approaching 50 years old, my struggles have been since puberty. The dream of nice legs is gone forever. **Please, please, realize that this is a real battle.** I felt that once I lost the weight, my legs would magically look normal. **I am defeated, embarrassed, and hopeless. Lipedema/lipodema is REAL!**

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## VALERIA VINCENT SANCISI

### Berkeley, CA

In July 2020 it will be two years that I have lived with lymphedema. Six weeks after surgery I was on a hot hillside with a potential client for landscape design. Got home, looked down, my whole right leg was huge. My surgeon really was not much help except suggesting I needed a physical therapist. The one she recommended was away for three weeks so I tried my GP and he referred me to one that only used her hands to drain, no advice, etc. Kept searching and found a clinic that had more resources. They helped quite a bit and when we finished the sessions, they gave me a machine with a sock that inflates.

But my own research helped me the most. Swimming, herbs, low inflammatory diet get the best results. **It has been very difficult to learn that lymphedema is a progressive disease I will have for the rest of my life.** It has forced me into premature retirement, as a landscape designer, both being in the field and in front of a screen is detrimental at a full time schedule. I can't earn and I need to. So I am living with financial stress, stress of managing my every day, that when I wake up and stand, it is countdown for when it swells I have to wear and pay for out-of-pocket, expensive compression garments that limit me in hot weather. You get over-heated and swelling occurs. It has dashed my dreams and plans of travel (I am a life-long traveler). Emotionally that has been one of the hardest realizations and a big part of my identity.

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## RACHEL WHITING

### Standish, CA

My son Lane was born in 2006 with a diagnosis of fetal hydrops, which is fluid everywhere. The neo-natal doctor told us they could keep him alive 3 days. Miracles happen and he is 13-and-a-half now. But when we left the NICU there was no diagnosis, just suggestions of doctors to visit. One of those suggestions was a lymphatic specialist. After three months of searching I found a doctor to take my baby too. His office was 7 hours away. He has been a literal life saver. He gave us compression treatment options and dietary restrictions but said there was no research or money in lymphatics so there wasn't much to look forward too. All the compression equipment, orthopedic shoes, etc., were not covered by insurance. Lane has been in out of hospital with pleural effusions, pericardial effusions, and has had two major lung surgeries and countless draining procedures from the edema and fluid. The infusions he takes now cost \$350 a month after insurance. **Lane is a lively boy trying hard to breathe everyday. Finding a cure would mean a new and better life.**



## KACEY WOODMAN

### San Francisco, CA

When my baby cousin was born in August 2016, his birth was met with lots of joy but also fear as the doctor was concerned with swelling in his body that was at the time undiagnosed (later diagnosed as congenital lymphedema). Once we were able to meet him, we were so in love with the cute boy but still worried as no one knew what treatment could be done nor what complications could arise in the future.

Currently his lymphedema is managed by custom daytime and nighttime compression garments. He is a big trooper wearing these and his parents sacrifice to make sure they are able to continue to get him more as he grows. He is an active, sweet boy and our family would love to have more answers to make sure we're caring for him in the best way we can.

## KATHIE WOODMAN

### Lafayette, CA

My nephew was born with lymphedema almost four years ago. He is an amazing kid and so full of life and fun. His lymphedema primarily presents in his feet, legs, and hands. He requires special shoes to be made since nothing on the market will fit his severely swollen and rounded feet. He also has to wear compression pants and gloves. It's not only difficult finding compression garments that help alleviate the symptoms, it's also very uncomfortable for him in the heat. **Can you imagine wearing compression pants and gloves on a hot summer day?** The risk of infection without the garments is also very worrisome. **A cure for this disease would bring**

**comfort and quality of life to so many who suffer from it.**

And for our boy, we would love better treatments and optimally for a cure to be found so he can be his energetic, fun, witty self, without the worry that comes with this disease.

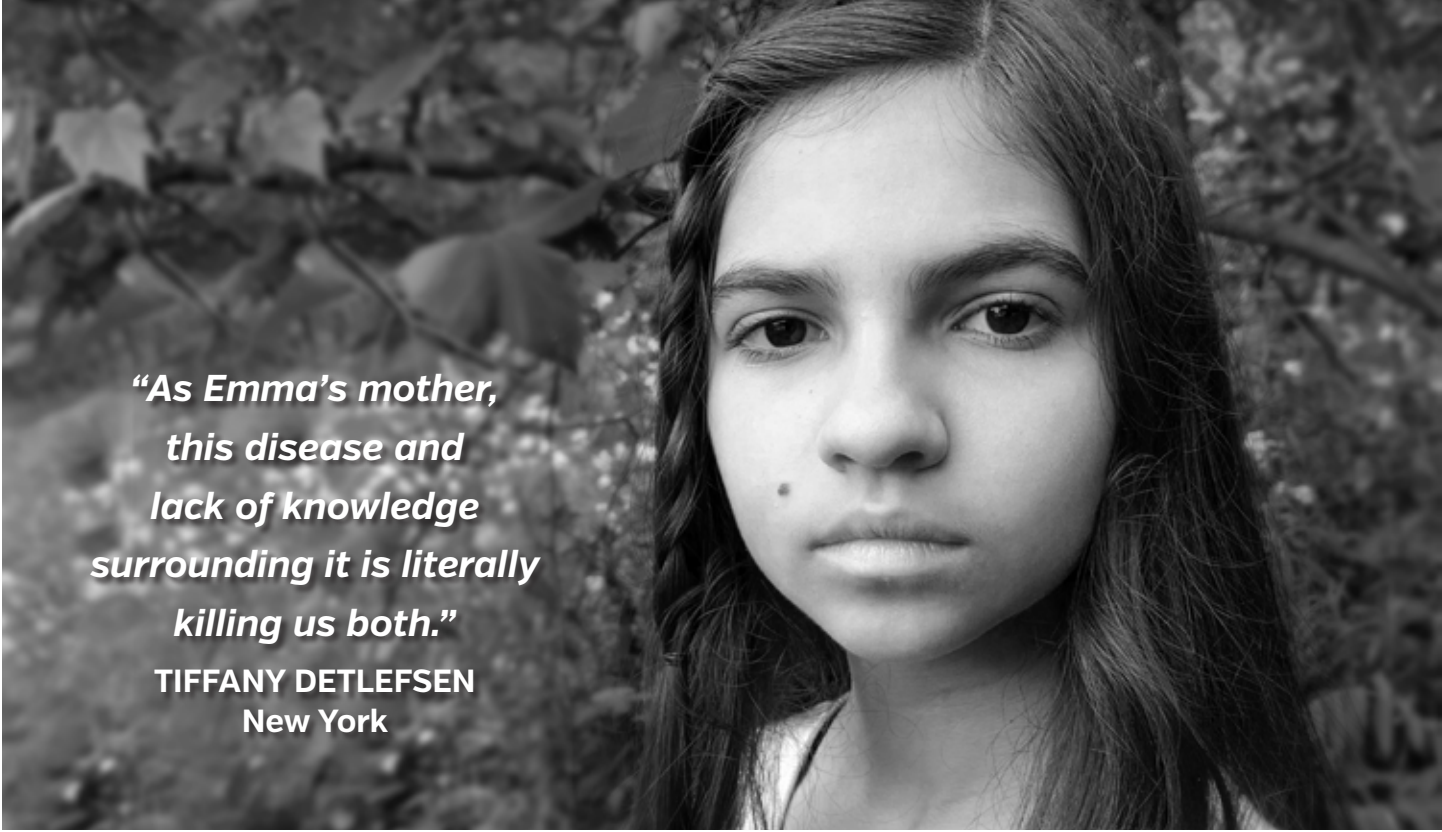
## MARIE APODACA

### Colorado Springs, CO

My journey with lymphatic diseases started around puberty. **I went misdiagnosed for almost 20 years before I became my own advocate and wouldn't just take "You need to eat more salads" as the answer for why my legs were getting exponentially larger than the rest of my body.** I dove head first into all things "lymphatics" as soon as I found an answer for why my legs were getting larger, heavier, and had infections that couldn't be addressed by simply eating "more salads." I was honored to speak with the CEO of the American Medical Association in 2016 to make him aware of how we desperately need the upcoming doctors to learn more about the lymphatic system. I have helped raise over \$48,000 for research into lymphatic diseases; but I soon found out that there is so much more needed for others like me.

Unfortunately, insurance doesn't pay for most of the therapy, medical garments that I (and others like me) NEED to control these lymphatic diseases. There are NO other options for anyone like me dealing with lymphedema and lipedema other than physical therapy and garments. This is UNACCEPTABLE!

**I plead with Congress for myself and other lymphatic patients to help us to find a CURE for these diseases! You would want the same for those you love!** We just want the same chance to live without deciding between groceries and medical care for these diseases we NEVER asked for.



*"As Emma's mother,  
this disease and  
lack of knowledge  
surrounding it is literally  
killing us both."*

TIFFANY DETLEFSEN  
New York



## EMILY DAVID

### Colorado Springs, CO

I am a 40 year old female and have congenital lymphedema of the left leg. After my birth, my parents were told I would likely die or at least that I would never walk. I didn't die and I can walk, run, and jump. I have been seen by medical professionals from the Mayo Clinic and the University of Minnesota. After years of exploratory testing and surgeries, I was finally diagnosed my senior year in high school. At that time, I underwent Lymphatic Massage Therapy, which helped to control the swelling but unfortunately became cumbersome, time consuming, and did not fit my teenage lifestyle.

In the 22 years since, I have only managed my lymphedema with compression garments. Even still, at the highest level of compression, the garments do not adequately control the pain, pressure, and swelling.

**The level of fear attached to a lymphedema diagnosis is also prevalent in my mind. I am very careful with my leg to ensure I am free of clots and cuts. To me a cure would mean freedom from swelling, pain and fear, a heightened level of confidence and self-esteem, and a reduction in other medical issues possibly related to my lymphedema.**

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## ANGELA MARQUEZ

### Lone Tree, CO

I have secondary lymphedema in my legs due to cervical cancer treatment in 2007. I underwent a hysterectomy, chemotherapy, radiation, and had thirty-six lymph nodes removed.

My lymphedema presented in March 2016, nine years later, with swelling in my left ankle. Within a week my entire leg was swollen and I could not fit in my shoes. After a series of emergency room and doctor visits, I was diagnosed with lymphedema.

After my diagnosis, I immersed myself in research and realized attention needs to be brought to lymphedema and lymphatic diseases. **I was shocked to learn that an estimated 10 million Americans suffer from this disease and yet it is rarely known, discussed, or understood—even in medical communities!** Additionally, lymphedema affects a significant number of our military veterans. You likely know someone either with or at risk of this disease. Not only is this disease painful and a financial burden, it also carries a heavy psychosocial impact due to disfigurement and ignorance.

I vow to do everything to raise awareness, to be an advocate, to work towards fair treatment and a cure. A cure would mean freedom for me and all those who suffer from this debilitating disease. **We ask that Congress prioritize funds for research and education to help us find a cure and help us overcome this disease.**

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## ANNE CAROLLO

### Milford, CT

My niece was diagnosed with primary lymphedema at age 11. **She didn't receive helpful medical care until she was in her twenties and did her own research.** She began seeing an

occupational therapist who specialized in lymphedema.

The treatment helped, but who knows how much better she could be if she received this help when she was younger? She worries about the future, how the disease will progress, the cost of the compression stockings, pumps, and nighttime garments she uses, and if her son and future children will inherit the disease. **A cure needs to be found.**

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## NANCY ERRANTE

### Branford, CT

My daughter was diagnosed with primary lymphedema at age 11. Her doctors said there was no treatment, and it might get worse. She saw her doctor every year, but they did nothing to help her. At 23 she became proactive to find an occupational therapist who specialized in lymphedema. The treatment helped, but if she had been treated from the beginning her results would have been much better. Instead, she now has irreversible, Stage 2 lymphedema and has physical pain and discomfort. It was not easy as a teen to wear compression socks.

Her lymphedema seems stable now, but she is only 32 years old. I worry about her health and mobility in the future, not to mention the cost of compression garments, pumps, and night time garments that she needs to manage the swelling. **A cure would give us hope for a healthy future and ease the anxiety of dealing and arguing with insurance companies. A cure would also decrease the worry about the possibility of her passing this on to her children.**

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## LEAH MORIARTY

### North Branford, CT

I met my best friend when we were six years old. About five years later, she was diagnosed with Lymphedema and it was scary for me as a kid to see my best friend go through that, knowing there was no treatment available for her. Despite being a healthy, active young person who saw her primary care doctor each year, she didn't get the treatment she needed until we were in our early twenties after she tirelessly researched and found an occupational therapist who specialized in Lymphedema. Now in our early thirties, she has irreversible Stage 2 Lymphedema. I worry about her health and mobility as we get older. **I wish treatment had been made available for her when we were kids.** We both had babies this year which has been such a blessing and so much fun for us. We have been best friends for 26 years and with a cure, I can rest assured we will live a long and fulfilling life together watching our kids grow up.

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## ALBERTA RICHETELLE

### New Britain, CT

When I was 10 years old I was stricken with polio, which paralyzed both my legs. I walked with long legs braces and crutches all through high school and college. When I enrolled in graduate school at the University of Illinois, I started to use a wheelchair because I had difficulty getting around the huge campus. I was very active, though, and competed in wheelchair sports on the national and international level, winning several gold and silver medals

I've never had a problem with swelling in my feet or legs. In 2015 my legs swelled up I was diagnosed with lymphedema. My legs are swollen and I can't bend my knees which makes it very difficult to sit in my wheelchair.

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## KERRI ROSSI

### Ridgefield, CT

Drew, our second daughter, turned 3 on March 9th. She was born with a swollen left foot. It soon was obvious to us that she was swollen on her left side from her waist down. **No one knew where to send us. This was extremely frustrating, anxiety producing, exhausting, and worrisome.** We continued to take her for testing, looking for answers, but nothing was confirmed. After a year plus of routine follow-ups, ultrasounds, and blood work, the definitive diagnosis was made in July 2018. We are so thankful to finally have a diagnosis: primary lymphedema. This means she has a congenital disorder causing a malformation in the lymphatic drainage system specific to this area of her body only. Instead of the body circulating and filtering lymph fluid throughout the body, the lymph fluid in this area collects in the subcutaneous tissues causing swelling.

**The challenge now is learning how to help Drew live with this chronic progressive disease. There are no treatments, just preventative measures.** She wears a compression stocking during the day, and a nighttime garment at night to help control the swelling. Our family is getting involved to share Drew's story in order to raise awareness, help other families without direction, and find a cure. She is an amazing young girl with a huge personality, and at a young age already an advocate for this disease.

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## YVONNE STOOPS

### Collinsville, CT

When I was 12 years old, one of my ankles became swollen. Fortunately for me, after ruling out any other possibilities, I was diagnosed with primary lymphedema. I say "fortunately" because I was to learn later how long some people live without a diagnosis. Soon after, my other ankle swelled as well, and I have managed my progressive condition by wearing compression stockings for the past 40 or so years. I was extremely self-conscious of my looks as a young woman, and I believe that this adversely affected and delayed my social development. Only with the advent of the Internet and research organizations such as LE&RN, have I been able to "tell my story"—because this became the only way I have even understood "my story" myself—and the only way I have been able to tell any doctor about it, not one of whom knew about it before meeting me. The financial hardship has been substantial and yet, because it has always been there, somehow, I have always budgeted for it. That was the status quo until 2016 when, for two years, I fought five successive bouts of cellulitis, three of which required hospitalizations. None of those were in the budget!

**The condition is progressive, and I am getting older. I can only hope that when I become eligible for Medicare and am on a fixed income when I retire, that I will be able to receive adequate care and treatment. Please vote YES!**

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## STACY VOTTO

### Guilford, CT

**I have watched my sister suffer with lymphedema for much of her life.** When she was diagnosed, approximately 20 years ago, there were very few resources to help her cope with and treat this ailment. As a result, her condition worsened over time and has negatively impacted her physically, emotionally, and financially. Increased funding and awareness will help people with this debilitating problem find relief and hopefully protect future generations from suffering needlessly.

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## KATHLEEN MULLIGAN

### Wilmington, DE

I developed lymphedema in 2015 from treatments for ovarian cancer in 2010. Before that, I acted full-time for 30 years on stage, in television, film, and commercials. I traveled, worked on new projects all the time, met creative people and used skills I had spent a lifetime honing. I supported my family, was active in my community, and even did the Avon 2 Day Walk for Breast Cancer nine times! I was a crew leader for Habitat for Humanity. I taught creative dramatics to children to share the joy of acting.

In 2015, that all ended. My leg swelled up to three times its size and I was completely sidelined. It took months to diagnose me and another year to find proper treatment. I have physical therapy two hours daily and wear compression 24/7. I can't work as an actor and can't do the physical things that I used to enjoy.

**I am told there is no cure for lymphedema. I don't believe that. Millions of Americans are held hostage by lymphedema. Please support research for a cure to free us from this captivity and allow us to live our best lives again.**

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## KIMBERLY GLOVER

### Washington, DC

I was born and raised in Washington, DC. I started experiencing swelling of my left leg after I had an inguinal hernia surgery. I was misdiagnosed for a couple of years, given fluid pills, and told to elevate my legs. After visiting about ten doctors, a definitive diagnosis was given: I was diagnosed with secondary lymphedema. **I was not properly educated on how serious or life-altering having lymphedema would be.** Currently, I'm in 24-hour compression, wearing both day and night garments, which is covered by insurance. I also use a pneumatic pump for an hour a day. I've definitely had a range of emotions, from feeling isolated to empowerment. I decided to use my life experiences on living life with lymphedema and lymphedema advocacy and share them on my blog at [www.Keepitmovindc.org](http://www.Keepitmovindc.org).

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## COLLEEN AUDETTE

### Micco, FL

After having a lymph node removed due to a melanoma on my arm, I got the OK from the doctors that all was good. Six weeks later my breast became red and swollen and I had fever and chills. I was given an antibiotic and it went away. This reoccurred 14 times



***“I am swollen and in pain. There is no cure and it is hard not to be very mad and frustrated.”***

**ZACHARY BERGER**  
Conroe, TX

in four years. **I went to nine different doctors to find out why this was happening and no one knew.** They just kept giving me antibiotics. Three breast surgeons, general surgeons, infectious disease doctors, dermatologists, gynecologists, etc., no one knew! I was finally referred to a lymphedema clinic and they trained me to do manual daily massages. I wear a compression garment all day everyday. **Doctors need to know more about this disease.** I haven't had any infections in two years since going to a lymphedema clinic.

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## **ROSANNE BESSENAIRE**

### **Melbourne, FL**

I am co-owner of Space Coast Lymphedema Clinic in Melbourne, Florida. **Lymphedema is under-recognized, under-treated, and misunderstood.** We have educated community doctors. We have gone from 10 new clients per month to 40 per month in the five years we have been in business. Medicare pays for therapy but, sadly, these patients need lifelong compression to maintain the decongestion to prevent potential life threatening infections. Many patients do not have the funds to pay for medical care and their condition worsens. Please pass the Lymphedema Reduction Bill Act.

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## **KIMBERLY BYLE**

### **Dunedin, FL**

I've had secondary lymphedema for over half of my life. But since I only had a five-year life expectancy after melanoma surgery, I feel lucky! That is, until I get stares when I'm out in public. Or the little

kid who points at my leg and asks Mommy, “What’s wrong with her leg?” And then there’s trying to buy clothes. Let’s not even go there! Lymphedema has caused me not only pain, discomfort, and embarrassment, but it severely impacts my mobility, my self confidence, and the forming of relationships. And since my insurance company will NOT pay for my compression garments or lymphatic treatments, it’s also financially draining! My primary doctor knows nothing about the treatment of lymphedema, and there are very few who do, given the lack of training given to medical professionals. So, let’s change that! **Let’s work together to get lymphedema and lymphatic diseases taught in medical school! Let’s educate insurance companies on the necessity of compression garments and lymphedema therapy and demand they cover treatment! Let’s pass some comprehensive bills in Congress that gives as much money to lymphedema research as other debilitating diseases! And yes, let’s find a cure!!**

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## **MELINDA CUNNINGHAM**

### **Chipley, FL**

I was misdiagnosed for seven years. I finally found a vein specialist that immediately diagnosed me two years ago. **This is an incurable but manageable disease. It is also very expensive! I have to pay for my compression out of pocket while on disability.** I am limited to what I can do mobility-wise. Anything that can be done to have Medicare pick up the costs would be helpful.



## DONNA FABER

### Ocala, FL

At age 55 I suddenly got lymphedema in my left leg. I've had this for twenty years now. My left leg is, of course, bigger than my right leg so I have to buy a special stocking, which is costly and requires a prescription from a doctor. I also buy leg wrappings and gauze to wrap the leg, none of which insurance covers. I have to take care of leg daily; if not it swells, aches, and leaks fluid.

**A cure would be awesome! So many people are enduring much pain, malformations, and expense. P. S. Shoes are hard to find when one foot is bigger than the other. Thank you for your time.**

## BRIDGET FORSTER

### Boca Raton, FL

I was born with primary lymphedema in both hands and arms and went 12 years without a proper diagnosis. **I lost 12 precious years of what could have been valuable treatment and management with compression garments, but instead was told there was nothing they could do for me.** Between having my hands called "hot air balloons" in kindergarten, and being avoided by kids for fear if they got too close they could "catch" my disease, I had to learn to develop a thick skin early on. I found a passion for tennis when I was seven, but having lymphedema made it tough as the name-calling continued. But worse than that, traveling to different climates and by plane caused unwarranted swelling or even heat exhaustion.

There is not enough funding and support for lymphedema and lymphatic diseases. My hopes is that our stories can raise awareness and make lymphatic diseases known, but to also ultimately achieve the means for research and someday find a cure. I was lucky and am now able to manage my lymphedema, but there are thousands of individuals living with chronic lymphatic diseases that do not have what they need. Nor do they have the medical and financial support their disease requires to maintain a high quality of life.

## ANNALEA GRAY

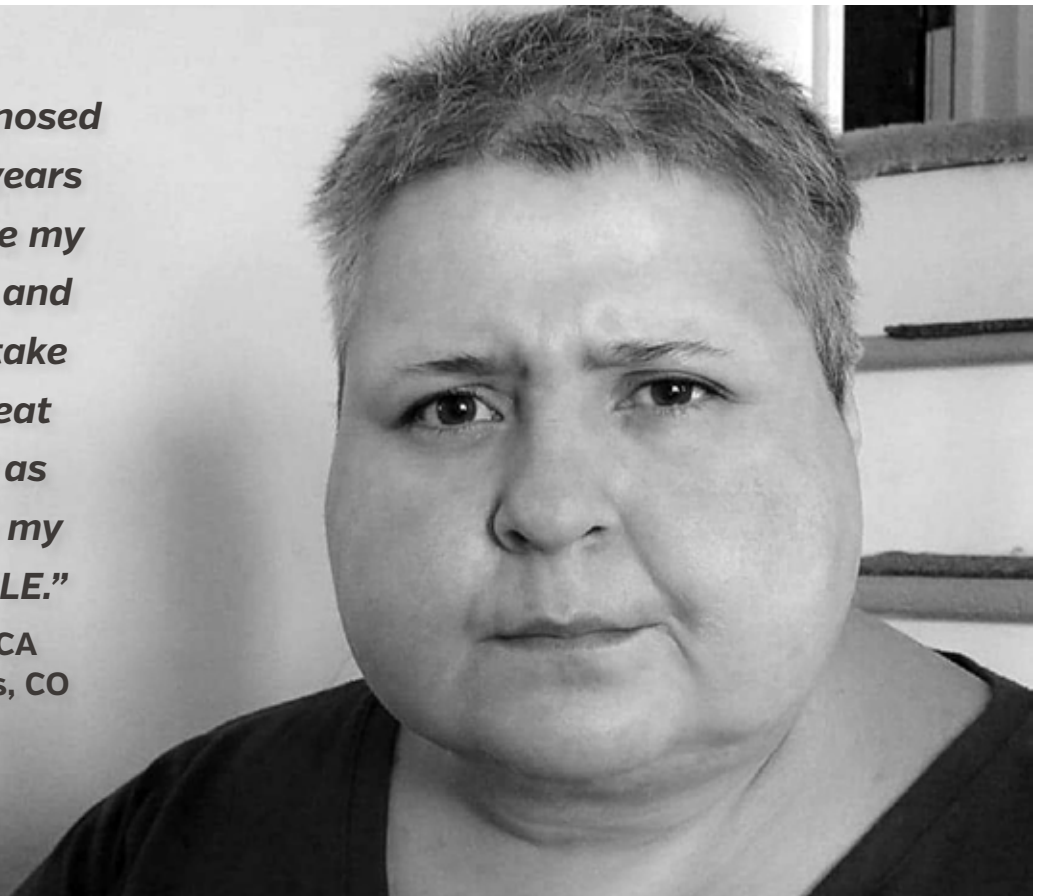
### Tampa, FL

I'm 41 years old and started showing symptoms of lymphedema at age 15. I went to numerous doctors but none knew what was wrong. At 23 I was diagnosed with Primary Lymphedema. I've had recurrent cellulitis (serious bacterial skin infections) over the last 17 years. I'm unable to do activities like go to the beach, wear heels/boots, or walk long distances. I've had numerous visits to the ER, hospitalizations, infectious disease treatments, and IV antibiotics, costing myself and my insurance thousands of dollars. These costs would be significantly reduced for thousands of individuals if Medicare & health insurance companies covered preventative compression garments.

I paid \$850 for one pair of custom thigh highs but my insurance only covers cancer-related lymphedema. Those patients only make up a fraction of cases. Garments are expected to last only six months before needing replacement. This is a lifelong condition with no cure and an expense for the rest of one's life. **Please take**

***"I went misdiagnosed for almost 20 years before I became my own advocate and wouldn't just take 'You need to eat more salads' as the answer to my lipedema and LE."***

**MARIE APODACA**  
Colorado Springs, CO





**action! You'd be saving patients thousands of dollars and insurance companies millions as good compression is the best prevention for recurrent bacterial infections and hospitalizations.** Once a person experiences cellulitis, their lymphatic system is further damaged making them more susceptible to infections. A vicious cycle. **My four year old was also diagnosed with primary lymphedema. It pains me to know he has a lifelong struggle ahead of him with little research and no cure in sight.**

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## **SHEILA JARVIS**

### **Lake Wales, FL**

20 years ago, I was diagnosed with lymphedema at age 49. I was very active before that and I walked three miles a day. I was lucky to have good insurance and able to have compression stockings, wraps, nighttime wear, and a compression machine. I have had many infections and hospital stays, which included kidney failure and sepsis. I am now on penicillin daily so that I don't develop any more infections and DIE.

My main reason for writing this is not only for myself but for all the people that have this extremely debilitating disease and have no insurance. If they cannot afford all the garments that insurance pays for they are shortening their life span and they are losing a lot of good quality life.

Before I had lymphedema I had a great healthy active life. Now I can barely walk out to the street and back and I have to sit down. I can't go shopping, bowling, golfing, or doing any of the fun things I did before. **Please work on a cure and include in Medicare the garments needed for people with lymphedema to keep the swelling down. People are getting worse everyday because American government won't take care of their tax-paying citizens. Thank you.**

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## **HANNAH WALSH**

### **St. Petersburg, FL**

**Growing up, the hospital felt like my second home.** I don't remember too much about all the procedures but do remember traveling to MD Anderson in Houston. I saw a lung specialist there and right away he knew I had a rare, incurable LD—Pulmonary Lymphangiectasia. He ordered a lung biopsy, which confirmed my condition. I was in the hospital for seventeen days due to a pleural effusion from my lymphatic disease. As a result of this disease, I developed a secondary condition—Primary Immunodeficiency. This has affected my life more on a daily basis. I was diagnosed around six years of age.

Over the next few years I missed a lot of school due to sickness. I had to repeat a grade. Ultimately my parents and doctors decided to pull me out of school to be quarantined. At the same time I began (IVIG) immunoglobulin therapy that consisted of six-hour transfusions every three weeks at the hospital. This helped stabilize my health and lasted for almost ten years until I was introduced to subcutaneous (Sub-Q) home therapy which changed my life!

I was cleared to attend my junior year of high school. This has proved to be an exciting time for me. Recently, I got my first job,

volunteer at a Hospice, and graduated from high school. I still do sub-Q once a week; my health is steadier and I'm happy. I'm concerned about the future, though, because there's no cure for my disease.

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## **RAMON DORTA**

### **Jefferson, GA**

Greetings. My name is Pastor Ramon Dorta, In 2009 I traveled to Peru and contracted a flesh-eating bacteria which, through bad practice, completely destroyed my two arms. This bacterium at the same time ate all my muscles and lymphatic system and every time I go to medical emergencies they do not know how to work with my case since I am the only existing case. I currently live in Georgia and I am a Christian pastor from the Hispanic area.

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## **CRYSTAL GARRETT**

### **Atlanta, GA**

My name is Crystal Garrett and I have primary lymphedema. Primary lymphedema is the localized swelling of the body caused by an abnormal accumulation of lymph or in other words, body fluid. I was born with this disease and it became visible when I turned 14. It makes my left leg and foot look like I have a sprained ankle all of the time but, in fact, it's a disease that causes a visible deformity and many problems in my profession as Miss South Carolina 2007 and as a model/actress/singer.

In my profession I am expected to look great always, and by great, I mean by society's standards of beauty. My goal in life has always been to strive towards excellence in everything but having lymphedema in the entertainment industry makes that incredibly challenging. For example, I secured a modeling campaign for a big brand name and hid my swollen foot well for a couple of photo shoots, except one. When the photographer noticed the swelling in my foot, he pointed it out to the brand, and I was not asked to come back again. **This disease affects my livelihood and my ability to provide for my family. I need a cure. I need those who could affect change on a higher level to care. I need your help.**

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## **JON BENNETT**

### **Honolulu, HI**

My mother has dealt with LE for years following cancer treatment. While the expenses and lack of healthcare coverage hurt, the emotional toll of being told that there are no treatments and that insurance has no intention to help is a much greater burden on us all. After attending a National Lymphedema Conference, I can say without a doubt that LE patients are the most impassioned advocates for support of those experiencing these complications. **These conditions are truly lacking awareness in the medical community and I hope that we continue to fight for greater awareness and support for advocacy and research to help reduce the economic, physical, and emotional burden on patients and those at risk.**

## SHARON SWEETMAN

### Post Falls, ID

I had four back surgeries in 2016. The lymphedema came on slowly but I am now unable to attend church and leaving the house is almost impossible due to the pain.

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## CINDEE THOMPSON

### Orofino, ID

I have Primary Lymphedema in both legs. It takes my whole day to manage but now I have open chronic wounds due to not being able to afford custom garments. **Medicare does not cover even part of the expense! Instead, I have to go to wound clinic twice a week. How is that cost effective??**

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## LYDIA DEMPSEY

### Glendale Heights, IL

I woke up one day at age 33 when my life flipped around. I was diagnosed with a disorder of degenerative disc disease and I have had eight back-related surgeries. As a result of those surgeries, I now have lymphedema in my legs and feet. I have problems keeping a job and keeping pain at bay with flair ups. I'm afraid of using salt, any salt. I cry daily in the shower from frustration and pain. I'm 46 but feel like 86. No help from doctors or insurance—are you kidding me? This crippled me and I get no help? My life is over and I feel I ruined my husband's life by marrying him. Honestly, it's so sad that no one will help out this disease or whatever this hell is called. It's sad that this is not taken as seriously as other similar illnesses. It's also so financially draining! Tons of money spent on compression socks, pants, and wraps. So many on the market are no good or don't last long. Being told that it's fixable if one gets treatment quickly but irreversible if ignored too long! What!? My doctor doesn't take it seriously enough, just says to wear compression socks. What? I can't even get socks on me! I'm not happy that people don't care enough?

**People shouldn't have to live in skin they are being tortured by. Skin is largest organ of body. This should be a huge priority for research.**

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## BARBARA LAMBERT

### Granite City, IL

I am a teacher, mother, grandmother, wife, and breast cancer survivor. Now adding caretaker of myself to that list. It's fine, I can handle it. **But living life after cancer should be joyful. Sitting in a lymphedema pump EVERY DAY is not joyful! Taping, washing garments, and trying not to complain is not joyful. Paying for all of this is not joyful. The fact that doctors don't know enough about it to help is not joyful. I don't want to be just a survivor. I want what you have: the possibility of enjoying my life again.**

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## DR. SHERI PRENTISS

### Chicago, IL

**I was a successful practicing physician, overseeing the Occupational Medicine and Employee Health Departments of the largest healthcare system in Illinois when a diagnosis of lymphedema completely disrupted my entire life.** Breast cancer treatment left me disabled from lymphedema in my right upper extremity, stripping me of my life-long dream of being a practicing physician. I was subsequently terminated from my executive management position while on FMLA during physical therapy for treatment of my lymphedema, and I had to completely reinvent myself after 16 years of clinical practice.

I went on to become a best-selling author and highly sought after physician leader, but my journey was not without its challenges. Lymphedema was a secondary blow to my physical and emotional well-being. I wondered if I would never be able to get on with my life. I experienced high levels of psychological, social, sexual, and functional morbidity. **Witnessing the disparity among African American women with this disease, I created a 501c3 nonprofit organization, the LIVE Today Foundation, Inc., which provides free compression garments to under-resourced cancer survivors living with lymphedema. I also support other grassroots organizations, like LE&RN, that are making an impact in the lives of individuals with this disease.**

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## BECCA SAJBEL

### Palatine, IL

My name is Becca. I am 26 years old and have primary lymphedema in both my arms and legs. I found out at 13 through a bunch of tests. I couldn't run like the other kids, had a hard time fitting in, and couldn't move as easily. **Lymphedema has robbed me of my life.** I don't have normal functionality in my legs and arms. I can't get regular treatment because even with insurance it's too expensive. I can't get equipment I need and I can't get new garments every six months like the doctor tells me. I have a hard time fitting in at the workplace and getting accommodations. I can't walk very far. I can't get in and out of my car that easy. Again, I'm 26. I shouldn't have these issues. **I should be able to manage a horrible disease with affordable healthcare. Doctors don't even know what this is! They spend a day—tops—learning about the lymphatic system and meanwhile people like me suffer with improper care and no cure. Do something! Help me so I can have a better life and maybe even be able to share it with someone else. I'm 26.**

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## DIANE SCHUMACHER

### Springfield, IL

I was an eight-month baby and lived with constipation my entire life. Nine years ago, at the age of 64, lumps started appearing on my legs. Home remedies seemed to keep them under control. Then my mother died four years ago. After getting home from the one day wake and funeral in Chicago my legs had swollen like balloons and were weeping liquid like a waterfall. A trip to the ER got me admitted to the hospital for a three day stay. After first telling me

my heart was strong they later told me my heart was the cause of my problem and I needed heart surgery. Because of the discrepancy I sought a second opinion where I found the correct diagnosis to be lymphatic disease. That doctor, an internal medicine physician, helped me quite a bit but got to a point where he could do no more for me. I have not been able to find another doctor who can help me and my legs are again swollen to the point where walking is close to impossible. **When I seek help from local doctors they check my heart, find it OK, then tell me there is nothing wrong with me. It is terrible being sick and nobody recognizes the disorder. That should never happen in a town with a major medical school. Someone needs to help me before it is too late.**

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## JAMIE CAMPBELL PETTY

### Martinsville, IN

Through several friends with lymphedema, resulting from their cancer diagnosis/treatment, I have seen the significant and painful impact on their lives. There must be more funding to help the millions who suffer with lymphedema. They deserve the means with which to have a better quality of life, which would be accomplished by proper research and resulting treatments and cures. **Please support funding for necessary research!**

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## NANCY KAY FRANK

### Noblesville, IN

I have witnessed, through friends and family, the impact on quality of life as a result of lymphedema. In particular, two friends were diagnosed with lymphedema as a result of cancer diagnosis and treatment. **Please support appropriate funding for research to find a treatment. These people need your assistance to ensure they enjoy a good quality of life. Thank you!**

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## GUY PETTY

### Martinsville, IN

Through several friends and family with lymphedema, resulting from their cancer diagnosis/treatment, I have seen the significant and painful impact on their lives. There must be more funding to help the millions who suffer with lymphedema. **Please support funding for necessary research!**

## KATIE BOLSINGER

### Cedar Rapids, IA

When I was 50 my legs started filling with fluid. I was sent to several specialists and run through many tests to try and figure out why. I was finally sent to Dr. Wei Chen who informed me that I have lipedema, which was causing my lymphedema. He told me I have probably had lipedema my entire life. I have struggled with my weight since I was little. My self esteem was always low because I thought I was a weak person because I was always overweight. I think if doctors were more aware of this condition I wouldn't have struggled so much my entire life with dieting and hating myself. I am still finding other issues I have that relate to this. Many symptoms that doctors just blew off because they didn't understand it was a result of lipedema. One of those symptoms is pain and with my weight increasing due to the lipedema, my pain is also increasing. **If liposuction was allowed through insurance, I could have less pain and a better quality of life. Also, now that I know what diseases I am dealing with, I could better manage any recurring lipedema and slow future progress.**

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## MINDY BOWEN

### Coralville, IA

I am a Lymphedema Nurse Specialist. I have seen this disease disable and destroy patients lives. I have seen the sadness in patients eyes when they are told their insurance won't cover the diagnostics, the therapy and garments, or the surgical interventions to help them. None of these patients asked for this disease; it is secondary to cancer treatments or primary lymphedema that they have no control over. **As a nurse I say we need to do better! We need more education and more research. This isn't a disease that should be ignored. Let's move forward, don't be oblivious to this disease! Let's be proactive!**

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## VALERIE BRIGGS


### Shawnee, KS

As a certified lymphedema therapist, I have received five misdiagnosed lymphedema cases in the last six months. These patients, private and public insurance companies have wasted valuable funding on a wrong diagnosis, due to a lack of lymphedema education. One patient in particular, a 27-year-old male, was referred out six times, ending in an oncology referral without even one diagnostic test. **Had the medical community been better supported in lymphedema education and funding,**

***“Let’s pass some comprehensive bill in Congress that gives as much money to lymphedema research as other debilitating diseases. And, yes, let’s find a cure!”***

**—Kimberly Byle, Dunedin, FL**





***“A cure would mean  
no more infections,  
no more hospital  
stays, no more  
restrictions, no fear of  
losing your leg and  
not being able to do  
what you love.”***

**CONNOR LOOBY  
Mahopac, NY**

he would have a better outcome and spent far less on his private, state, and federal insurances. Please take this chronic disease seriously and improve the quality of healthcare in our country.

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## **REBECCA DAVIS** **Somerset, KY**

I had never heard of lymphedema, nor had an abnormal Pap test until November 2007. After a radical hysterectomy and 28 radiation treatments the journey began. I do not remember exactly when the swelling started, maybe early 2009. My right knee began to swell, and swell, and swell. Then the left knee. Two swollen knees. **I lost count of the number and types of healthcare professionals that saw my knees. Not one knew what the issue was!** Maybe a fatty tumor, maybe a diuretic would help. “Do they hurt?” (Not then.) “If they start hurting, come back and I will see if I can figure out what to do for them. Otherwise, just leave them alone.” And so it went until April 2014.

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## **SUSAN MAGEE** **Bogalusa, LA**

I began suffering from lymphedema two years after my hysterectomy at age 34. No one knew how to treat it. I came across a wonderful surgeon who did lymph node transfer. It worked but I still need compression stockings to maintain the fluid reduction.

Medicare does not cover these and the customized ones I need cost almost \$1,000! We need your help!! Thank you!

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## **SUZANNE PHELPS** **New Orleans, LA**

I had uterine cancer, and following a total hysterectomy, radiation, chemo, and several lymph nodes removed, I ended up with lymphedema. **No one had mentioned this condition as a possible side effect, even after observing the swelling in my legs. When it was finally diagnosed, I realized there is no cure! Cancer gone, lymphedema here for the rest of my life!** Now, following PT treatments and bandaging, I was told three times that I had contracted cellulitis. And three times following antibiotic treatments, the doctors realized that it wasn't cellulitis but rather a skin issue due to the treatments. **Long story short, not enough is known about this condition nor are we, the patients, told about the possibility of having this condition beforehand and what to look for. At least that way, I could have started dealing with this condition earlier.** It has affected my clothing and shoes that need to fit over my leg and feet, which stay swollen all day, everyday! I use compression stockings all day, use a leg pump for one hour every night, and go to bed with a cushion leg sleeve (toe to thigh high) all night. Please help us help others. There are really no seriously good options for us once this condition is diagnosed. Thank you!



## MARJORIE YESLEY

### Blue Hill, ME

**Living and coping with lymphedema for the past 15 years has been an experience I'd prefer to have missed.** Diagnosed with LE four months after surgery for breast cancer, with both arms swelling and extremely painful, I began thrice-weekly manual lymph drainage sessions. Even with the relief these treatments offered, I soon found that I could no longer lift or handle the boxes of music that were integral to my job in a music library. I also could no longer play or teach the piano because of the pain traveling through my arms and chest when I physically pushed the piano keys. (I started piano at age four so this has been horrible for me.) I was classified as permanently disabled and could no longer work.

Now, 15 years later, I also can't shovel snow or lift my grandchildren or rake leaves—or do any movements that involve some pressure or resistance, like washing windows. I still wear compression sleeves every day and have MLD treatments every month. Although my lymphedema symptoms are now more under control and tolerable than originally after my mastectomy, I continuously wish for a better, more permanent treatment or cure. And, at 72, my time is running out! **Research is critical to easing the lives and bodies so compromised by this disease; mine is just one of them. Please help to make lymphedema research possible.**

## ZALEE HARRIS

### Hughesville, MD

In August, 2014, I was diagnosed with Stage III IDC Breast Cancer in my left breast. I elected to have a double mastectomy. A few months later, I began having terrible pain around and under both armpits. I was diagnosed with OT Stage II Lymphedema in both arms. I was told that there is no cure. I will have to wear vertical and horizontal compression garments 24-hours a day for the rest of my life. The pain is so unbearable that I must change into the vertical garment within 20-minutes of being vertical. I use Fentanyl Patches and brand Lyrica for chronic pain. I see an OT Specialist once every six months. I cannot lift, pull, or tug anything that either weighs or has a torque over five pounds.

**I am 62 years old. Medicare recently informed me that I have to pay 20% on garments and equipment prescribed to manage Lymphedema that I am measured for every six months. I currently owe \$4,000.00 (20%) for three customized garments, which I cannot afford to pay. I cannot dress or undress myself. I need help bathing. I cannot comb my hair. I cannot put on socks and tie my shoes. A cure?**

## HANA-BASHE HIMELSTEIN

### Baltimore, MD

**Shoes.**

What really sets me apart from other women—normal women—is my shoes. Most women my age have a substantial collection of footwear for every occasion: different colors, patterns, heights, styles. Fancy. Basic. Athletic. Choices. *Not me. I own one pair of slip-ons.* Years of damage from stagnant lymph created a cuff above my ankles, making it impossible for me to wear ordinary pumps or

flats. And there isn't anything I can do about it. No exercise, pill, diet, surgery or therapy can reverse the damage caused by decades of untreated Primary Lymphedema.

Symptoms were present when I was a child, but were usually dismissed or a diet was prescribed. I only received a definitive diagnosis in my late 40s but, by then, the damage was done.

Treatment was assigned: compression, compression, compression! Otherwise, I'm resigned to living with this exhausting, embarrassing, sometimes painful—but always-misunderstood—condition.

**Thanks to LE&RN, there's a chance that lymphedema and related conditions will be (cured?) (eradicated?) (understood?) in my lifetime. I support LE&RN's efforts, contribute what I can, pray. Now I'm asking Congress to increase funding for research.**

**What would you do if you were in my shoes?**

## BETH MEYER

### Kensington, MD

In 2013, our family's life changed dramatically. My 9 year-old daughter Sarah's ankle swelled dramatically. A scintigraphy at Children's Hospital, DC. confirmed she had primary lymphedema—no lymph node activity in her right leg and foot.

The DC specialist gave no guidance so we got a second opinion three month later in Cincinnati. We learned that lymphedema is a chronic condition, maintained through MLD and hose. Sarah has hose, a night garment, and a pump she uses nightly. Her right leg looks double the size of her left.

Sarah has lobbied on Capitol Hill for the *Lymphedema Treatment Act (LTA)*. She inspired a bill for Maryland Insurance to cover compression garments that became House Bill 847. She was nominated as a Rare Disease Teen Advocate in 2018.

In 2018, my older daughter Hannah's left leg looked swollen the day before a vacation. At home, her diagnosis of primary lymphedema was confirmed. Recent testing shows Hannah has no lymph node activity in her left leg and foot.

**Our family lobbies for LE&RN and the LTA. Hoses and massage just maintain the disease; they don't cure it. Lymphedema takes a toll on self-esteem, quality of life, and can lead to death. Education, research, better insurance, and eventually a cure are imperative.**

## MICHAEL PROKOPOWICZ

### Baltimore, MD

My name is Michael P. and I am 10 years old. At the age of six years old, I was diagnosed with Kaposiform Lymphangiomatosis. It is a really big word so I just say KLA. It is also very rare but it affects kids like me at my age. It can make me really tired and I have to be careful when I play because I bruise a lot. The doctors and scientists do not have a cure yet but with me telling my story and sharing what I have been through with others I really hope that the experts will work together, get lots of funding and research dollars, and help me and kids just like me. **Please know that we are all #bettertogether and that we need to put #puthopeintoaction.**

## ARNIKKA ROBINSON

### Upper Marlboro, MD

I have primary bilateral lower extremity lymphedema. Although dealing with it for much of my life, I was officially diagnosed with it at the age of 22. I am now 40 years old. MLD therapy and compression garments allow me a quality of life, enable me to rear my children, and afford me the opportunity to work. **Coverage of such medically necessary items makes sense on both a humanitarian as well as fiscal level.**

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## THELOISE FERRELL

### Ashburnham, MA

I had breast cancer and a mastectomy when I was 33 years old. Fifteen years later, I developed a swelling in the affected arm. **My doctor had no idea what was causing this and thought I had phlebitis.** I developed cellulitis twice and had 30 days of antibiotics both times while teaching full time and wearing a heparin lock.

The swelling continued so my doctor sent me for an ultrasound. The technician who performed it said what I had was called lymphedema and gave me a handout and the name of a physical therapist at Leahy Hospital, 45 miles away. I had just started a new job and my principal kindly arranged my classes so that I could travel (75 miles in all) to the clinic for treatment and then to work. There were no local treatment centers. I currently wear compression garments and a heavier night garment to maintain my lymphedema. My arm is weak and I now have neuropathy and neuralgia in my left hand. **I hope for more advanced research and better guidelines disseminated to doctors regarding treatment of this disease.**

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## CATHERINE HOLLEY

### Quincy, MA

In 1988 I was a nurse in a large, Harvard-affiliated Boston hospital. A physician said, "Your right leg is swelling, I don't know why. Take these water pills, it will help." It didn't. It was 20 years before I found a clinician trained in lymphedema therapy and treatment. I've lived with this disease in my leg for 32 years. THIRTY-TWO YEARS! With every decision or choice I make in life, the very first thing I consider is the impact it would have on my leg. This is second nature to me now, like breathing. **Many with lymphedema are disfigured/disabled and are unable to live a normal life. Social distancing and isolation aren't new for them, they've lived with it for years.** Despite tremendous advances in many areas of medicine, the fact remains that in 2020 the only thing I can do to move lymph fluid out of my leg is to literally wrap it daily with several layers of bandages—unbelievable. **This is just my story. There are millions of others. Let's find a cure together. I'm happy to help. I'm currently working at Mass General Hospital, a battlefield for COVID-19, and so proud to be a nurse. Thank you.**

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## KARI FORMSMA

### Jenison, MI

**Finishing my surgery, radiation, and chemotherapy for uterine cancer, I thought the worst was over. I was wrong. Five months later, I looked down at my grossly swollen leg, beginning the challenge of my life coping with lymphedema.** Management involves 2–3 hours a day, robbing me of 100% of 'free time', especially when I struggled to remain employed. Leg heaviness makes it difficult to walk. The 23 hour-per-day need to wear compression (bandages or tight custom-made garments costing \$5000+ per year) makes my joints stiff and painful. I know if I let up in this care, my future is a nursing home.

**I have found zero physicians in Michigan treating this disease, scant medical research, and inadequate funding. There is a desperate need to train more providers to treat lymphedema.** Requiring insurance coverage of supplies/services is vital to avoid progressive deterioration resulting in even more expense to the individual, family and society, in addition to the waste in human potential. Most importantly, research is need to prevent and cure this common, chronic and neglected disease. I would love to return to being a highly productive person again, rather than spending so much of my life on coping with lymphedema.

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## LARRY HEMBROFF

### Jenison, MI

My wife survived uterine cancer. After completing surgery, radiation, and chemotherapy, she developed lymphedema in her left leg and buttocks. Even with treatment, she is unable to remove all the daily accumulating lymph. Her affected leg is roughly 50% larger than her other, adding about 15 pounds to that one leg—like walking around with two full gallon-jugs of milk strapped to your leg!

To prevent worsening, she must continuously treat the leg with compression bandages and garments. Daily she must unwind the 90 feet of stiff bandages wrapped over foam she wore during the night, put on tighter but less bulky custom-made compression garments (@ \$1000) she wears during the daytime, take off the garment in the evening, roll up the bandages, put on the foam and wraps for the nighttime, launder the used garment, wraps, and foam for their next use. **Altogether, this takes 3–4 hours each day. Every day! When home, visiting family, or traveling. For the rest of her life.**

The lymphedema, wraps, and garments restrict her wardrobe and mobility, limiting what she can do with the time she has. She survived cancer. Treatment side effects rob her of much of the life she was spared.

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## MONICA HUBBERT

### Brighton, MI

I have been an occupational therapist who has specialized the management of lymphedema since 2013. I have encountered many individuals who have been directly or indirectly impacted by lymphedema. **Unfortunately, I continue to see the same issues because lymphedema is still treated like a sprained ankle versus a chronic disease.** This is most evident when our third party payers

provide hard narrow limitations on things such as garments, time with experts, and other supportive services. **I hope that organizations such as LE&RN can facilitate the drastic changes needed in the definition of lymphedema and its management.**

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## PAULA JOHNSON

### Detroit, MI

I had breast cancer surgery in August 2012. I was diagnosed with lymphedema in 2013. **My insurance company denied my request for a pump requested by my therapist.** My left arm is almost twice the size of the right one. I suffer each day, and cannot get any treatment. I've had physical therapy for it, wear the sleeve. Nothing helps. **No one seems to care or take lymphedema seriously.**

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## THEODORE KUNG

### Ann Arbor, MI

I am a fellowship-trained plastic surgeon with a strong interest in helping patients with lymphedema. At my hospital, there are many patients with lymphedema secondary to cancer treatment (particularly breast cancer) but recently insurance policies have denied almost 100% of the authorizations to perform lymphedema surgery. Patients from Michigan are electing to travel to different states to undergo lymphedema surgery even when skilled surgeons are available and eager to help much closer to home. Insurance companies need to understand just how

burdensome lymphedema is and their policies on covering lymphedema surgery should be updated. **Physicians, like their patients, need support from Congress to enact this change in order to really fight this challenging and chronic condition.**

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## CECILIA MUND

### Wyoming, MI

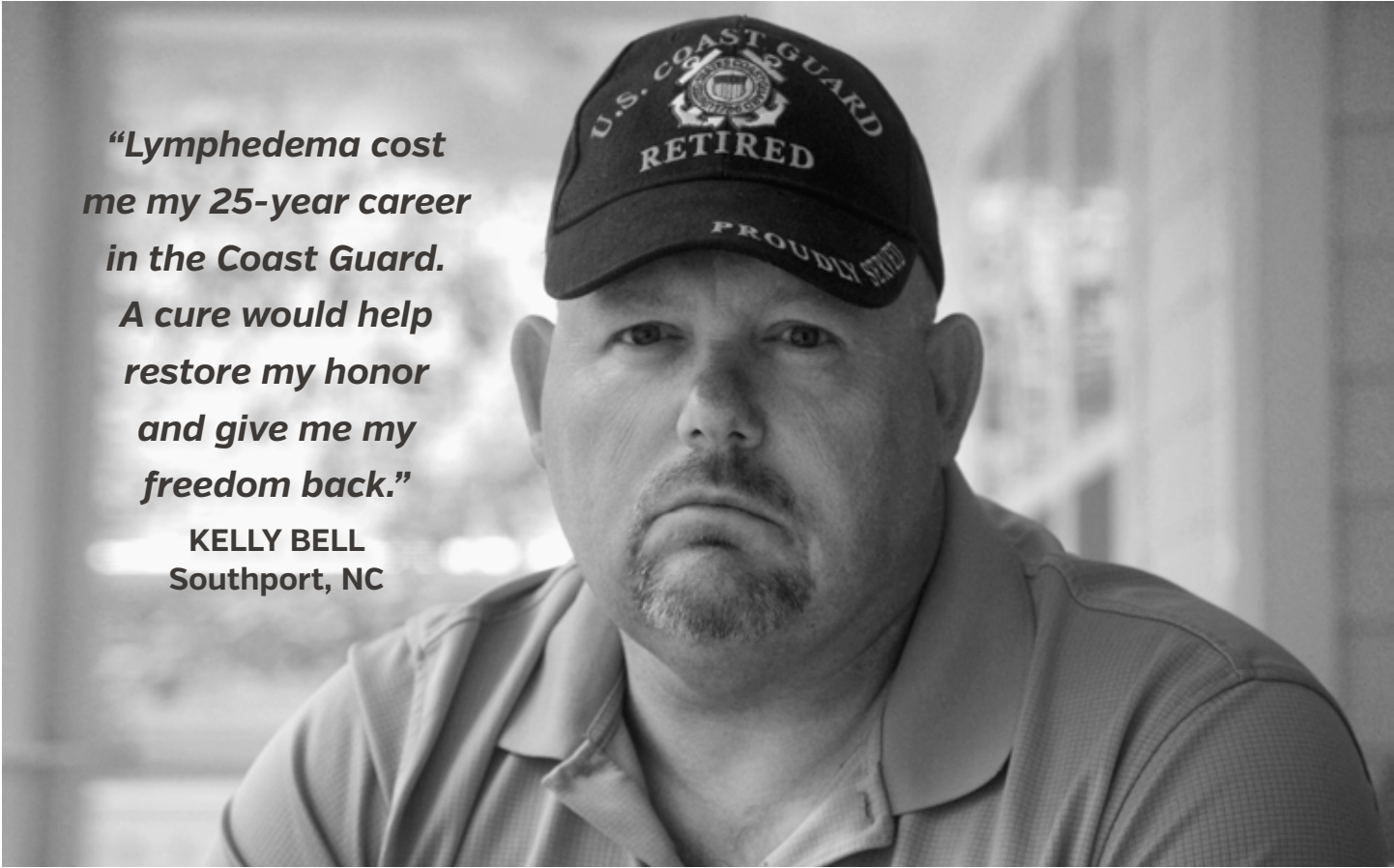
I was diagnosed with lower extremity lymphedema after treatment for cancer when I was 30, almost 18 years ago. In the past 18 years I've had to give up my career, I've lost friends, struggled with pain, discomfort, body disfigurement as well as body dysmorphia, depression, and exhaustion. I have suffered tremendous financial burden because none of my compression garments are covered by insurance. **Lymphedema is a nightmare and it ruins lives. We need help and we need it now, please.**

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## AMANDA ROOT

### Burton, MI

**I have secondary lymphedema from cervical cancer. I have struggled with misdiagnosis and unknowledgeable medical staff for ten years.** I have been unable to see a therapist due to the high cost and I am in need of new compression. I was just recently able to receive a free consultation and have been diagnosed at a Stage 2. Now during the pandemic, I am unable to seek treatment and I am currently fighting a cellulitis infection as a result. I am not even able to go to the hospital at this time. Not having the tools that are



***“Lymphedema cost  
me my 25-year career  
in the Coast Guard.  
A cure would help  
restore my honor  
and give me my  
freedom back.”***

**KELLY BELL  
Southport, NC**



beneficial in fighting this chronic illness can be detrimental. **Being able to access proper medical care and garments would reduce so many unnecessary infections and illness. Please help me in the fight against lymphedema.**

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## RENEE PLEMMONS

### Appleton, MN

My story with LE started years ago when my legs started swelling for no reason. My doctor thought it was from my fibromyalgia and said, "I believe you have edema." But he wasn't sure which kind. So after years and years of living with my legs feeling so heavy—and feeling the retention of water building up in my legs and then my arms—I finally needed to see a specialist. **Now I am receiving LE therapy and I have this amazing machine to help as well. Problem is, it all costs so much and my insurance only covers part of it.** I used to be able to walk for miles and now I get tingling pain in my legs and swelling after a block or so. Standing more than five minutes causes great pain. This has prevented me from doing so much daily. I'm uncertain if my LE was caused from all the accidents I was in as a child or from the four C-sections. But I am hoping that my story helps others to understand the pain so many of us have to deal with.

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## ELIZABETH SIMMER

### Saint Paul, MN

At age 36 (20 years ago) I found a lump in my breast. It ended up being cancer. I underwent surgery (lumpectomy), radiation, and four years of Tamoxifen. Before surgery, I was told I might get something called "lymphedema" either from the surgery or during radiation. I noticed swelling right away after the surgery in my right arm. I was a lucky one. My physician sent me to a physical therapist immediately and I was educated on what lymphedema was, how to manually massage it, how to wrap my arm, and was sized for garments. In hindsight, the fact that my lymphedema was recognized immediately and taken seriously was amazing. This was 20 years ago (2000). I've continued to have physical therapy support during flare ups, education on keeping my arm healthy, and care and support from my physician. **I'm a lucky one. All people deserve this type of education and my insurance pays fully or 80% for my care and garments. This is how it should be for all people. I need my right arm and without all of the care, time, and attention I give it, I would be unable to use it.**

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## EMILY GOFF

### Oakland, MS

I have struggled with leg pain since I was a little girl. After crying night after night, my parents took me to doctors. They were told it was "growing pains" and I would outgrow it. I didn't. I wasn't diagnosed with lymphedema until after age 55. **So little is known about my disease that even doctors had no idea!** I finally was fortunate enough to find a primary physician whose wife also struggled with lymphedema. He sent me to his hospital for treatment. I live in a rural area and traveled nearly two hours each way, three times a week. Because insurance doesn't cover it, and I lost my job, I could no longer afford treatment. **Treatment helps a**

**little but we need a cure! We need education so that more doctors don't just say, "You're fat, lose weight." Please help us!!!** I wake at night with pain, have arthritis in both knees, and because I will not heal because of lymphedema, I cannot have knee replacement. The pain is unbearable most days. I beg of you to educate and do more research to find a cure!!!

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## JACKIE BARNETT

### Columbia, MO

**I'm 49-year-old breast cancer survivor and I have lymphedema in my arm, hand, and breast due to cancer treatments that saved my life. I'm grateful to be here, but my new normal now involves exhausting daily care (manual lymph drainage and using a pump one hour every day) in the hopes of stopping this regressive disease and avoiding cellulitis and sepsis.** I have annual expenses for arm sleeves, gauntlets, and bras. None of these costs are covered by insurance and requires nightly washing and care. I have to be careful in the sun, can't exercise like I used to, and my daily care takes time away from my loved ones. My life has changed. **But the scariest part is that doctors barely understand this disease and its impact. There needs to be funding for those of us who deal with this daily, funding for research and an increased emphasis on this disease and the lymphatic system for medical students and nurses.** I am blessed to be in early stages, for now, and fully employed, for now, but my future scares me with this disease. Please, please, please pass this bill to improve care and resources for a disease that affects millions of people.

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## CAROL FULLER

### Manchester, MO

In 2016 I was diagnosed with breast cancer. I had chemo, a double mastectomy, surgery, and radiation. I lost most of my right side axillary lymph nodes and now I have lymphedema in both arms, and in my trunk. I need a minimum \$210 worth of compression garments every six months.

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## CINDY McDONALD

### Columbia, MO

I thought lymphedema was a disease for unfortunate Africans bitten by mosquitoes, until I developed it in both legs after pelvic lymph nodes were removed due to uterine cancer. I thought celiac was a disease that only affected sickly starving children, until I was diagnosed with it at age 53. I thought I was fat and lazy, even though I was continually dieting and exercising, until I discovered I had Lipedema and Hashimoto's Disease. All of these diagnoses happened to me within a few months in 2014, and suddenly my world was completely affected—from the food I ate, to the clothes and shoes I wore (which now included the awful, ugly, thick black compression hose from waist down to my toes), and even to the chairs in which I sat. All were changed as a consequence of my body turning against itself with these incurable progressive autoimmune disorders. **I could not be more shocked at the reprehensible lack of knowledge of my oncologist and family medicine practitioner about the above-mentioned diseases and disorders. I have had to educate myself completely, as well as advocate for any treatment. This needs to change! Find the cure!**





***“Living with lymphedema is a daily challenge. Kids at school don’t like to play with me because I can’t jump as high and run as fast.”***

**KAITLYN TANG**  
Dublin, CA

## **ANN ROSS** Ballwin, MO

I accidentally fell while I was skiing, tore a leg muscle, and got lymphedema as a result of the lymph vessels not healing perfectly aligned. **It’s a lifetime disease.**

## **TARA PARKER** KalisPELL, MT

I am a 33-year-old mother of two who has been dealing with lymphangioma since I was 11 hours old. I have been to Seattle Children’s Hospital and the Mayo Clinic to receive treatment but, unfortunately, there is no cure. They all say what I have is genetic, so every day I am afraid that my boys will soon have to go through the same suffering I have. My lymphedema is in my right leg up into my abdomen, which affects my every day life, I’m not able to stand for long periods of time or sit for long periods of time so it makes it very difficult to do anything. As much as I try to keep it down it continues to grow and the pain also continues to grow. **I have lived with this condition for so long that my lymph system no longer works so there are no other options other than just maintaining.**

## **AMANDA BERG** Valley, NE

16 years ago this month, I was bitten by a brown recluse spider in the computer lab on my last day of college. This day shaped my life

in more ways than I could have ever expected. The venom had quickly traveled through my lymphatic system in my right leg and shut my lymph nodes down. My leg gradually began to swell and it continued to move up my leg. I spent weeks in and out of hospitals and doctors offices trying to figure out why. That’s when I met Dr. Penn at UNMC. He told me I had developed lymphedema. **I had no idea what that meant, along with most doctors and medical staff for that matter!** Every day for 16 years I have had pain and discomfort given that my right leg is about 50–60% larger in size than my “good” leg.

I honestly thought it couldn’t get worse until I went in for my 33 week perinatal appointment and found out my daughter had lymph fluid sitting on her lungs. I had an emergency C-section and they drained as much fluid as they safely could out of her tiny fragile body. I spent two long and emotionally draining months in the NICU by her side. Sophia fought so hard to push out the remaining fluid and I prayed to God it wouldn’t come back. She just turned one last month and thankfully has not shown any signs of it coming back. **I now pray more than ever that my baby girl will not ever have to go through any of this. I would do anything to protect her from this. Please help us find a cure.**

## **RHONDA BRANNAGAN** Grand Island, NE

I am submitting a story for my daughter, as she doesn’t have computer. She has had severe lymphedema, especially in her legs, but it is now progressing to other parts of her body. She would be so thankful if they could find a cure for her lymphedema or at least

a medication that would help it. It seems to me that it is a disease that most doctors don't know much about. It is a very debilitating disease and there doesn't seem to be much except compression and physical therapy to help it. **I urge Congress to study this disease more and to pass legislation for some kind of help for the people who suffer from it. Thanks.**

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## TESSA WARNICK

### Geneva, NE

I was 18 years old (in 2000) and developed a deep vein thrombosis in my leg after three weeks of being on birth control pills (that I did not want). After 12 years of doctors shrugging off my concerns with the swelling, I finally received a diagnosis of lymphedema (LE) in 2011. Last year (2019) I needed surgery and now my leg swells more easily and faster than ever. **My story has been forever changed in ways I never imagined it would be. So many things I can't do now that I once took for granted. Please help find us a cure.**

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## CAREY HAWS

### Spanish Springs, NV

I am a breast cancer survivor and I live with lymphedema every day since my breast cancer surgery four years ago. Managing lymphedema is my full time job, every single day, with no time off for holidays. It is not something I signed up for or would want anyone else to have. **Lymphedema affects every aspect of my life, every single day. It makes being a Special Education teacher for 35 years look like a walk in the park and a piece of cake, all rolled up into one!**

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Being that my glass is half full, never half empty, AND having a tremendous amount of resilience and perseverance, I started a Lymphedema Support Group in Reno, Nevada to help others stricken by this horrific disease. We meet monthly and have guest speakers on timely and pertinent topics relating to the disease. My goal is to have Kathy Bates as a guest speaker one day. She is my hero and the inspiration that I can do this and deal with lymphedema every single day of my life.

**A cure for lymphedema would mean that I, like many other Americans, would get my life back. I believe a cure is attainable in the foreseeable future. It cannot happen soon enough for me and so many other Americans.**

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## BRIDGET BENJAMIN

### Bellmawr, NJ

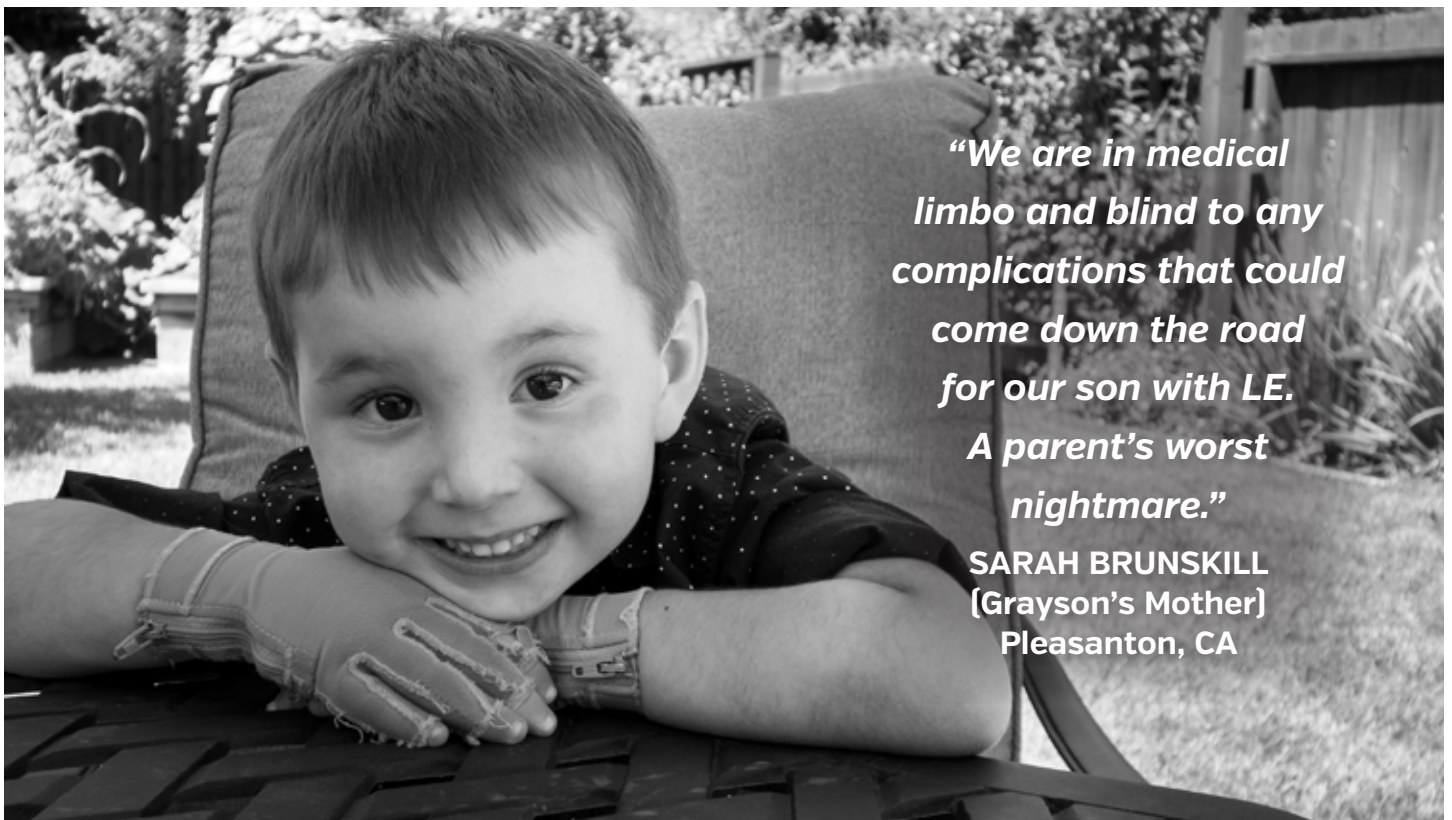
When I had surgery for uterine cancer, I had no warning that the removal of 15 lymph nodes could lead to lymphedema. In 2008 I noticed my left leg was starting to swell. I was not given precautions to protect myself from developing this horrible condition. I now live with a leg that is twice the size of the other, causing me pain, depression, and embarrassment, not to mention problems in buying trousers and shoes.

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## DEBORAH CLARK

### Newark, NJ

All of my current chronic pain issues were non-existent prior to the hysterectomy I had in 2002. Among them was lipedema; which was not diagnosed until 2015. After years of suffering with very painful



***“We are in medical limbo and blind to any complications that could come down the road for our son with LE. A parent’s worst nightmare.”***

**SARAH BRUNSKILL**  
**[Grayson’s Mother]**  
**Pleasanton, CA**

***“The scariest part is that doctors barely understand this disease and its impact. There needs to be funding for research and an increased emphasis on this disease and the lymphatic system for medical students and nurses.”***

**—Jackie Barnett, Columbia, MO**

swollen ankles and legs, the real battle started with trying to get treatment. The initial wrap therapy—which I had to ask for, and only knew about from friends who had relatives with the same condition—works very well, but once the wrap is removed, the swelling returns. For ongoing treatment you need to wear compression garments, which includes socks and various undergarments. The coverage for therapy is limited, and the supplies are not covered at all. I am retired early because of this condition.

**I am a senior on a very limited income. I am still wearing the same special order socks from therapy of three years ago. I still suffer with the painful swelling, and I cannot afford massages, or other at-home exercise equipment.**

## **AMY FAIRWEATHER**

### **Wantage, NJ**

I developed secondary lymphedema in my left leg 12 years after having 29 lymph nodes removed during a total hysterectomy due to cervical cancer at the age of 31. This was just after my second daughter was born. **Nobody ever mentioned, or even discussed, the possibility of lymphedema happening back then and it took years to get a diagnosis.** This disease needs more advocates and more coverage! There are not enough healthcare providers and the compression garments and treatment options are antiquated!

## **KAREN WARING**

### **Toms River, NJ**

I am 78 years old living on a fixed income! I've had lymphedema for years, and because I couldn't afford treatment it's gotten worse! I really feel like I will be dying soon! I really need help. Thank you!

## **LILLIANA MUNOZ**

### **Deming, NM**

I am 23 years old and have primary lymphedema on my entire left side. I have been getting treated for it since I was 14, but I've had this condition since I was 9. **For five years I was sent to numerous specialists—from bone to blood—and the lack of knowledge by medical professionals about lymphedema caused mine to get worse over time.** Once I was being treated, we found out my insurance didn't cover the most important tool in managing this condition: the compression stockings. I was raised by my great

grandmother who didn't have much and couldn't afford these stockings. To this day I still can't afford them. I work a full time job and pay all my bills on my own. I don't have money to spare to pay for my necessary stockings.

## **DEBORAH BAXTER**

### **Olean, NY**

I was diagnosed with breast cancer in September 2016. I had a right mastectomy and right axillary dissection. In January 2020 my right hand, fingers, and arm started to have swelling to the point my shirts were tight on my right arm and I had a lot of tightness, heaviness, and pain in my hand and arm. I went to see my oncologist and she recommended physical therapy. However, there is no one trained in lymphatic drainage within two hours of me. **I'm in desperate need of a cure for lymphedema.**

## **CLARE CHOLLET**

### **Elmira, NY**

A little bump on my ear led to metastatic squamous cell skin cancer and resulted in a radical neck dissection, removal of 79 lymph nodes, radiation, and chemotherapy. The loss of hearing was taken care of by a hearing aid. The quality of life issues due to having to do manual massage, wear compression garments, and use a pneumatic pump nightly—not to mention physical therapy by a certified lymphatic therapist 45 minutes away and the time spent doing these—have changed each day and will for the rest of my life. In addition, I have leaking of fluid, swallowing problems, and issues of physical appearance. **Since little research is done on neck cancer and lymphedema, there has been little help so far. Please help now.**

## **PATRICIA CORNUTE**

### **Saratoga Springs, NY**

I was diagnosed in 2007 with primary lipedema, and because it took so long to get properly diagnosed, I also have secondary lymphedema. They call my stage Lipolymphedema. **It is a chronic and progressive condition over most of my body, and I fight every day to maintain my mobility, which this condition tries its hardest to take from me.**

It's estimated that over 10% of the female population has Lipedema,



but yet most go undiagnosed, even 80 years after the first case was diagnosed at the Mayo Clinic. Instead we are fat shamed, made to feel it is our lifestyle, and get told we need gastric bypass surgery. The sad truth is that gastric bypass would only work on the regular fat, but even it cannot improve the Lipedema tissue.

We stay as active as possible, not in the hopes of losing weight, like someone without our condition would expect. But in the hopes we can maintain our mobility. But it is a continual fight that later stages are losing more and more. We need research, we need treatments that work, not just self care treatments to manage the symptoms, but real treatments to stop the progression, and hopefully one day find a cure.

We spread awareness as much as possible, so others can get diagnosed sooner and not share in the later stages of this debilitating condition. Thank you for listening and hopefully helping with funding for much needed research.

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## MARIANNE DEANGELO

### Massapequa Park, NY

My daughter was diagnosed with lymphedema at the age of 28 and sought treatment at a facility specializing in this disease. These centers are few and far between. The facility has now closed (reasons unknown) and we are looking for another physician specializing in this area. I am a registered nurse and very concerned about the lack of resources available. Thankfully my daughter, now age 40, is a responsible adult and does everything she was taught to keep it under control. We do not know what the future holds. There are many others who have not had the benefit of the education she received.

I have seen first hand what lymphedema does from my days working in hospitals. It can be terrifying. We need funds for education, treatment and research. Insurance companies need to expand coverage for needed supplies. The money spent would probably offset money spent used to treat related psychological issues and, I suspect, lead to less unemployment benefits paid to people who are unable to work.

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## EMMA DETLEFSEN

### Berne, NY

My name is Emma. I'm 11 and I was born with primary lymphedema in my legs and feet. I'm a youth ambassador for LE&RN because we need more knowledge and research about the lymphatic system and eventually we need a cure. Most of the time I can live a normal life except for having to wear compression all the time. But when I get sick with cellulitis, I miss out on life for weeks at a time. I've had 13 cellulitis infections and I've been hospitalized 9 times. Unless we can get the government to fund more research to find a cure these numbers are only going to get bigger. I try not to let it get to me but it is actually a really sad thing. I'm doing my best to try to fix things for everyone who suffers. I try to be the change. I have lobbied in NY and DC since I was seven and attended over 50 congressional meetings so far. I fund raise for a cure with my own lemonade stand and try to help pass bills like the LTA that would help people afford compression. That's a big problem right now and an easy fix. But we need your help. We need a cure for lymphedema and all lymphatic diseases and with your help we can all find a cure together.

## TIFFANY DETLEFSEN

### Berne, NY

**Lymphedema is the bane of my existence.** In 2008, my daughter was born seemingly healthy. We first noticed her swollen foot at seven months old. She didn't get a proper diagnosis of primary lymphedema until she was 1 and 1/2 and by that time her lymphedema had progressed to both feet and both legs. **The next few years would prove to be the most trying, traumatizing years of my life. A lack of knowledgeable doctors, therapists, and insurance companies along with the struggles to find proper treatment topped with cellulitis infections and a very sick little girl, actually led to a PTSD diagnosis for myself. The disease and lack of knowledge surrounding it was literally killing us both.** We decided to take charge instead of letting it win and joined forces with LE&RN. The patients we have met along the way inspire us to fight harder everyday, but we can't do it alone. My daughter, Emma, and I raise funds for LE&RN every year, we lobby in NY and DC for proper insurance coverage and research funding every year. Emma's a youth ambassador and I chair the NY chapter, but really, I'm just a mom trying to fix her little girl. **Now, we need you. It's time to research the lymphatic system and find cures. We are so close to finding real answers which will not only cure lymphedema and lymphatic diseases but many other diseases as well. Please keep LE&RN's initiatives at the forefront of your agenda.**

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## BETH DORAN

### Fort Ann, NY

I've had lymphedema myself for the past five years after being diagnosed. **There is very minimal help or research being done on this terrible disease!** I have had cellulitis multiple times and my legs are difficult to heal. The doctors or wound care specialists don't know how to treat me. Most of the time it's, "Try this or try that." I have compression garments and pumps to help me and will soon start therapy again. **Please. I'm begging for more research to be done to help all of us who suffer from this. Something has to be done!**

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## NICHOLAS HERENANDEZ


### Riverhead, NY

My name is Nicholas. I am nine years and I've had lymphedema all my life. When I was a baby my mom and dad saw swelling in my body and took me to the hospital. I was there for a week. **My mom says the doctors did so many tests and still didn't know what was wrong with me and I was super sick.** It turned out I had "lymphangiectasia" in my stomach and some issues with my "lymph system." (I know, is that even a word! I still don't understand what those words really mean.) My mom said it was so scary but my doctor, Dr. W, was the best. He never gave up on me my mom said.

Until I was eight I had lymphedema in only my right leg. Last year my other leg really swelled up and it hurt so much. Now I have lymphedema in both legs and the doctors don't really know why. That's why I want doctors to do more research because there could be a potential to find a cure.

**It would mean a lot to me if they found a cure. The socks that I wear on my legs all the time are very uncomfortable at times**





***“This disease affects  
my livelihood and  
my ability to provide  
for my family.  
I need a cure.”***

**CRYSTAL GARRETT**  
**(Miss South Carolina 2007)**  
**Atlanta, GA**

(and “crazy expensive” my dad says) and I have to be careful not to get hurt. I love to play soccer so you can see my dilemma.

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## **HATTIE JOHNSON**

### **Cambria Heights, NY**

In 2016 I developed a lump on my thigh, at first I thought it was just a pimple. Within weeks it grew so fast my PCP told me she believed it was sarcoma and sent me to a surgeon. Within a month I had cancer and lymph nodes removed and two months of radiation. Then the pain and swelling started. I used to run and play with my grandchildren, now I can't walk fast enough to keep up with anyone. I have missed a lot of family functions because sitting or standing longer than ten minutes causes excruciating pain and swelling. Today I take pain medicine, do exercises, and pay for lots of equipment and compression garments I truly can't afford. For three and a half years I've had ups and downs but no cure. **My quality of life is so low and depression is part of my life. My insurance hardly pays for anything. I stopped therapy because I couldn't afford it.**

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## **JENNIFER & CONNOR LOOBY**

### **Mahopac, NY**

Connor was diagnosed with a rare lymphatic disorder at six weeks old. We were told there was no cure and minimal research about it. Connor has been hospitalized hundreds of times for infections, low immunoglobulin levels, and the reasons go on and on. When your child is known to every doctor and nurse in the hospital it is comforting he will get the care he needs, but also terrifying.

Connor has raised money for research, stood on the NY State Senate floor telling his story, and shared his story to the world. Research would mean a cure. **A cure would mean no more infections, no more hospital stays, no more restrictions, no fear of losing your leg (due to infections spreading to your bones) and not being able to do what you love.**

At 13 years old, Connor has overcome and fought harder than any individual I know. He vows to find a cure for all suffering from lymphatic disorders and urges you all to help him! Thank you.

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## **MARY PARGAS**

### **Pelham, NY**

In 2008, at age 51, I was diagnosed with uterine cancer. I had a total hysterectomy upon the advice of my GP, who also told me that would take care of it all. Less than six months later it had returned. This time I was told my chances of beating it were 50/50. **After 34 rounds of radiation and a year+ of chemo, I was set free without a word of warning about lymphedema, even though I had some early signs that I brought to the doctors' attention.** I was grateful to be cured and even with years of frequent followup appointments, I was never warned about how to avoid or recognize lymphedema. I had swelling in my ankle and foot if I stood too long, if it was hot out, and was told many people do.

In August 2019 my entire right leg “blew up” during my daughter's wedding weekend. It never went away despite elevating it and sitting out the dancing and celebration. It took several months on a wait list to see a specialist to evaluate my leg and recommend any therapy for it. I am still grateful to be living but mourn that it means the end of being able to stand long enough to finish a

***“A cure for lymphedema would mean that I, like many other Americans, would get my life back. I believe a cure is attainable in the foreseeable future. It cannot happen soon enough for me and so many other Americans.”***

**—Carey Haws, Spanish Springs, NV**

painting, to be much of a caretaker for my grandchild, or care for my garden lest I get bit or scratched and develop cellulitis. I can't go into NYC by train because it involves more walking than my compression stockings can hold back. **It makes me feel old too soon. And maybe it could have been prevented with the right care and information.**

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## **MELANIE SPEAR**

### **New York, NY**

I have secondary bilateral lymphedema of the lower extremities. Mine was caused by radiation. One doctor told me I couldn't possibly have lymphedema because it was on both sides! Another doctor told me the swelling was not lymphedema and I just needed to restrict fluid and sodium and keep my legs propped up. Another doctor told me the swelling would go away if I wore support stockings. I had essentially diagnosed myself and I kept persisting until finally I got confirmation and treatment. **It is a curse that never goes away. My joints are stiff and inflexible, my skin is fibrotic, and I can never find shoes that fit. It is a very painful, limiting condition.** I wear compression garments all the time. Insurance will only cover two pairs of garments at a time, which is woefully inadequate and they will not pay for manual lymph drainage.

**Doctors have no understanding and need to be trained to recognize this condition, as it is progressive and requires constant vigilance. There are millions of sufferers out there, few resources, and little hope offered. I believe a cure could be found if only this condition were properly addressed. It would mean a release from hell for all of us.**

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## **KELLY BELL**

### **Southport, NC**

**Lymphedema cost me my 25-year career in the Coast Guard.** My lymphatic system was damaged during a simple medical procedure which almost ended my life. The damage caused me to start gaining weight, which was presumed to be fat but was actually fluid building in my tissues. Due to the lack knowledge of the lymphatic system and what happens when it is damaged, I was administratively punished for “being overweight” while I was in the battle for my life. The honor I worked to achieve was significantly diminished. I was treated like I had suddenly become lazy and fat. For years I fought to have the test that proved my lymphatics were damaged and a statement, “We finally see what you have been trying to tell us.” And yet, that only helped with a

diagnosis. No one had any idea what to do with me. I was medically discharged from the Coast Guard.

**For 15 years, lymphedema has caused me to miss out on creating lasting memories with my family. My condition seriously limits my physical capability. A cure for lymphedema would help restore my honor, give me my freedom back, and give me a new future to look forward to.**

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## **PAT GRAINGER**

### **Cary, NC**

Two of the most thrilling moments in my life were the births of my daughter and my son. My excitement was dampened by the fact that I had a clot with each child; first the right leg and then the left. The surgeon explained the danger of leaving the clots alone and his recommendation was surgery to remove the clots. I had no idea that the removal would hamper my life style for the rest of my life. I immediately had swelling of the legs with a great deal of pain. The greatest thrill is to have your children run to you so they can give you a big hug. I never made a sound but I clenched my teeth to stop screaming. When my children squeezed my legs I'd want to scream with pain but I knew I couldn't do that to loving children. To add insult to injury most insurance companies were not willing to give any financial aid to pay for support garments, therapy sessions, and other unexpected expenses. I am more fortunate than many in that I did have some assistance financially and a good support network of family and friends.

**This disease is not requested by anyone and should be treated as seriously as cancer. Please search your hearts and think how you'd feel if this happened to your mother, wife, or daughter. Also men are affected so it could be a son or grandson who is stressed for life.**

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## **KAREN GRIFFIN**

### **Rural Hall, NC**

I have had lymphedema for 20+ years and have been hospitalized with severe cellulitis numerous times as a result. I have severe scars from massive blistering that could have been prevented had doctors known what to do with me! Instead, I was sent home while still suffering from major infection and needing IV antibiotics.

**Doctors rarely know what to do with this disorder. I have basically had to learn enough on my own to tell them how to treat me!** Compression garments help my leg swelling minimally. Any tiny scratch can lead to cellulitis, which for me causes dangerously high fever, extreme pain, nausea, vomiting, and leg

ulcers. **Lymphedema is common but the medical community remains clueless about any potential cure.** I was given diuretics by more than one doctor, and water retention is NOT the problem! There is much work to be done to find a cure and better treatments for lymphedema. It affects both those who have had breast cancer and people like me, who acquired lymphedema after working in a sedentary job for too many years. Please pay attention.

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## AMANDA HOWARD

### Catawba, NC

Although I do not have lymphedema, I have had lymph nodes removed, which makes me at risk for developing the disease. **It is so disheartening to know that if I were to develop it, there is NO CURE!** With proper research and funding, I feel certain that there is a cure to be found.

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## KARIN SIEBOLD

### Oak Island, NC

As a Lymphatic Drainage Therapist I regularly meet new clients who are dealing with lymphedema—mostly secondary—having come on after cancer treatment. Often, these clients have never been educated or “warned” of the possibility of developing lymphedema, so they fail to get treatment early because they don’t know what it is.

Recently my own mother developed Stage 2 Lymphedema following uterine cancer treatment. The sad thing is that it went on for four months before we were able to get her treatment. Four different doctors were told of her swollen leg and they did nothing. Now it’s bilateral, Stage 2, and extremely uncomfortable. **If the**

**medical teams providing her surgery and radiation had educated her on what to watch out for, this could be completely under control. That would mean comfort for her and fewer medical bills for the insurance company.** Speaking of which, she now (amidst all the medical bills) has to pay hundreds of dollars to purchase compression garments because Medicare won’t pay for them!

**Please do something to change the Medicare coding, and please do something to promote more lymphedema education to doctors, nurses, and the general public.**

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## JULIE SMITH

### Hillsborough, NC

After getting through a mastectomy, chemo, radiation, blood clots from the chemo port, an occluded BC vein, a broken leg, and a parathyroidectomy, I was just waiting for the other mastectomy (pandemic-postponed) and I thought I would be in the clear. I was wrong! **Lymphedema hit me like a ton of bricks. Because of the lack of research and knowledge about this disease, it may be scarier than cancer and in many cases, more debilitating, with EXTREME costs for society due to work loss and health care issues. PLEASE do more to help.**

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## CYNTHIA MAIROSE

### Cincinnati, OH

My experience with lymphedema began in 2016, seven months after my surgery for ovarian cancer. **The most disappointing and shocking thing for me was that no one in my healthcare team had mentioned that lymphedema was a possibility and no one was**



***“As parents, our challenge now is learning how to help our daughter live with this chronic progressive disease having no treatments.”***

**KERRI ROSSI**  
**(Drew’s Mother)**  
**Ridgefield, CT**



***“I believe a cure could be found if only this condition were properly addressed. It would mean a release from hell for all of us.”***

**–Melanie Spear, New York, NY**

concerned when the swelling in my lower leg appeared. I found out about lymphedema by searching and reading about it on the Internet. When I asked my oncologist, he wanted to “Wait and see.” I requested a referral to a lymphedema physical therapist who confirmed my condition, and I began wearing a compression stocking that day and learning the other daily care I would need to follow for the rest of my life.

Since my oncologist was an excellent and very caring doctor at a university medical center, I suspected that other cancer survivors were no more likely to hear about lymphedema from their healthcare providers than I had been. I continue to feel strongly that this situation needs to change. More research would help us understand the disease and bring more awareness of it.

Lymphedema takes a physical and emotional toll. Much of this toll could be avoided with the research and awareness to understand, treat, and prevent this disease.

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## **MARY C. ROSE-WALKER**

**Logan, OH**

I was finally diagnosed in 2015, after dealing with the effects of primary lymphedema for 30 years, since the C-section of my second child. Aging made it worse and, finally unable to walk, I sought treatment. Most of the OT and compression garments are not covered by my insurance. Luckily, my pumps were covered. **I have had to limit my work time due to lymphedema. This disease requires 2–3 hours a day to maintain the strength to function as a normal life.**

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## **FRANCI SCHWAB**

**New Carlisle, OH**

I developed lymphedema after having breast cancer treatment, which included bilateral mastectomy with lymph node dissection, radiation, and chemotherapy. I developed massive swelling and unbearable pain in my arm, hand, and chest. I wear compression garments all day and another compression garment all night. My daily regimen includes an hour of therapeutic exercise. I use a pneumatic lymph pump for an additional hour each evening. Manual lymph drainage done by my lymphedema therapist reduces swelling and helps relieve pain, but visits are restricted by my insurance. Medicare covers both lymphatic pumps and manual lymph drainage done by certified therapists.

**Compression is the missing critical component that is not covered. Without it, the fluid re-accumulates quickly, undoing any progress made by the therapist and pump. Compression has been proven to reduce complications, co-morbidities, hospitalizations and overall medical costs for us. More**

**importantly, compression has been proven to reduce the progression of this disease.**

As the facilitator of a Lymphedema Support Group, my concern is for so many poor, sick, young and elderly lymphedema patients living in pain. Their condition and lives deteriorate. They are hospitalized again and again costing so much more. It doesn't have to be this way! LE&RN can improve our quality of life!

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## **DEBORAH CROW**

**Oklahoma City, OK**

I was born with primary lymphedema in 1957. Physicians believed that there was little to be done about the swelling in my lower limbs. Untreated, my ankles, feet, and toes became disfigured. **Concerned about stigmatization, I rarely disclosed and never fully exposed my lymphedema. I forfeited many opportunities because I chose to hide, and hiding came at significant cost to my social, psychological, and physical development.** During my adult years, with better treatment available, I have managed to slow the progression of my disease.

I recently earned a Ph.D. in Educational Psychology. I studied the experiences of young adults who grew up with primary lymphedema during more contemporary times than I, amidst the development of the internet, and emergence of lymphedema as an important medical agenda. Their voices amend those of many lay and professional champions who recognize that lymphedema is an under-researched, under-recognized, under-insured, and under treated disease. **Unfortunately, their voices also indicate that in 2020, young people living with the disease still experience egregiously delayed medical diagnosis and inadequate treatment, even altering the trajectories of their lives. Funding research about the lymphatic system and lymphedema will have an impact upon the social, psychological, and physical aspects of people's lives.**

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## **ELIZABETH BAKER**

**Lake Oswego, OR**

I'm not sure how I got lymphedema. It started at 13. Before that, I had healthy feet and legs that allowed me to start on the varsity tennis team early. But once my legs and feet began to swell and hurt, my athletics came to a grinding halt. It wasn't until I was 25 that I got an actual diagnoses and some treatment ideas, such as compression socks. Before that, I suffered for more than a decade with pain and debilitating swelling.

Even now, at 44, I still have all the same problems and very few helpful treatment options. **And as I get older, it gets worse. It's impacted my quality of life in every way, from feeling**

“deformed,” to having limited mobility and pain. I’d love for treatment options to advance and be covered by insurance! It’s a real disease, and yet so few understand it, including the medical community!

## ELIZABETH BASACA Portland, OR

Our 9 year old daughter Naomi has lymphatic malformations on her left arm and hand. She had sclerotherapy when she was six months old and her condition was manageable for years, despite continued growth of her malformations.

Unfortunately, when she was seven she started to suffer from daily pain due to the malformations impeding on her radial nerve. She had debulking surgery at OHSU at age eight, which finally relieved her pain and physical therapy helped her regain use of the affected wrist. Wearing a custom made compression garment and lymph drainage massage (supported by a Certified Lymphedema Therapist) have also continued to help her but the reality is this condition has no cure. She still has new growths and regular childhood illnesses cause flare ups.

**How her condition will develop over the years is unknown and her medical needs are multifaceted. Without good health insurance, her medical expenses could easily drown our family in debt. Lymphatic diseases have a huge impact on so many lives, old and young, and our elected officials need to take action to improve our healthcare system to include better support for people like our dear Naomi.**

## SARAH MCCOLLUM Portland, OR

I was 25 when my left leg lymphedema presented itself and changed my life forever. I had just moved to NYC by myself to pursue a career in the fashion industry. It took me years to find doctors who could explain lymphedema to me, and years more before I could fully understand, accept, and confront this challenging condition. Since then, I have had three surgeries and one major cellulitis infection, and have felt the toll of my left leg lymphedema both physically and mentally every day. I’ve had to fight for my rights against insurance companies and medical facilities that don’t understand what lymphedema is or how to treat it

**It is simply not right that lymphedema is so under-recognized by the medical community and that treatments and support are not covered by insurance companies. I’ll never give up and will continue to fight for us to get the recognition and treatment we deserve. Lymphies unite!**

## KATHY MOREFIELD Bend, OR

I was diagnosed with secondary lymphedema while undergoing chemo following breast cancer surgery. I was lucky to be in a medical group that had a young LE physical therapist who had gone to surgeons requesting they send their breast cancer patients to her post-surgery. Before any symptoms occurred. I got an early diagnosis and started treatment immediately.



***“At age 6, I was diagnosed with KLA. I really hope that the experts will work together, get lots of funding and research dollars to help kids just like me.”***

**MICHAEL PROKOPOWICZ  
Baltimore, MD**

We had hoped the chemo was causing my LE and it would go away when that ended, but then came radiation. Seven years later I still have swelling in my right arm. I wear compression ALWAYS which keeps it manageable. I haven't suffered any infections or any of the horrible side effects I read about.

**I know my early diagnosis made all the difference. We need more awareness, more research, more trained professionals and, above all, insurance coverage (including Medicare) for treatment!**

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## KATHRYN BURKE

### Allentown, PA

I am grateful beyond measure to be approaching five years past the end of my treatment for uterine cancer. Unfortunately, that treatment caused LE in my left leg. After considerable trial and error, I came to manage my disease with regular exercise, careful food choices, using a compression pump, and wearing a thigh-high compression stocking. From the moment I awake and don the stocking before leaving my bed and the reverse at bedtime, I constantly think about managing my activities and all of the above to prevent flare ups. It's a full-time job. No days off. Ever! So, if there was a cure or treatment for LE, it would eliminate all those burdensome daily concerns. As well, I would regain confidence in my appearance and be significantly more active.

**But the most thrilling thing? I could once again sit. Yes, sit! Like most people do, feet on the floor, or legs or ankles casually crossed. No need to elevate my left leg! I could sit comfortably at my piano, my studio drafting table, in my friend's homes, at the movies, concerts, restaurants, in the car—all the places we take sitting for granted. I sometimes dream about sitting like I used to. A simple thing, until it isn't. Thank you for your time and attention.**

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## DOROTHY BYERS

### Danville, PA

I'm a human being that was born with primary lymphedema second to Turner's Syndrome. I have lived my life with all the complication of this swelling, seeping of lymph fluid out of both legs, and complications from having it in my bowels. **When trying to get some treatment, doctors state they don't know anything about this disease. Please help.**

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## RUTH ANN CLEVELAND

### Washington, PA

I was born with lymphedema (Milroy's Disease) in both legs and feet, as were my two grandchildren, ages four and five. My right leg/foot is worse than my left. **Lymphedema is horrible. Emotionally, for me every day it separates me from others.** I was made fun of as a child. Adults and children stare at me. My personality has been shaped by this disease. I try and hide my legs and feet because they are unsightly. I wish I was stronger. I can't imagine NOT trying to hide who I am. Actually, someday in heaven I won't hide. I will be free.

Physically, I struggle with pain, swelling, and hardness in my feet,

legs, and ankles that I can't explain. I have fought MRSA and almost lost my toe. **A cure would set me free emotionally and physically!!! It would give me peace knowing my grandchildren would not have to live my life. A cure would mean hope, maybe not for me (I'm 56) but for future generations. There are no words to describe what a cure would mean. Just writing this I feel emotional...Just tears of joy. A deep gratitude in my heart. Freedom. Please Congress, help all of us who suffer!! Thank you!**

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## COLIN CONNOLLY

### Pittsburgh, PA

Lymphedema lurks in the shadows of well-known diseases but its effect on everyday life is devastating, as I can personally attest to. It requires an army of people to emerge from their own darkness to join together and raise a united thunderous voice of awareness and relentlessness. Congress, we need you to be the beacon of hope, to facilitate and lead our army so that our children could have a fighting chance. We've been neglected by everyone—including the medical community—for generations as our conditions and situations, physically and monetarily, worsen by the day. Please help us, lead us, and help turn the tide for patients throughout the country. **As someone who has had this disease for over 30 years and has seen many other patients suffer daily, I know that we need your leadership because we can't do it alone. Let's seize this opportunity and change the world for the better for millions of Americans. Thank you!**

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## PAULA KANCIANIC

### Pottstown, PA

I am a 61 year old RN who underwent chemo, surgery, and radiation for breast cancer in 2016. **That was traumatic, but developing lymphedema as a result of lymph node removal in 2018 has been more difficult since there is no cure.** The effects are visible to all, and the treatment is visible to all causing me to have to continually explain to folks why my arm is wrapped. It's exhausting emotionally and affects my self image. The garments are expensive, therapy with a lymphedema therapist requires a \$50 copay each time, and they want to see me daily when I have a flare up. I have a hard time physically tolerating the garments.

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## AMBER KELLY

### Carlisle, PA

My cousin's son, Grayson, was born with lymphedema. He is one of the sweetest most playful children I know. Grayson has learned to move and operate like a fairly normal kid but knows that his whole life centers around his lymphedema. His diet, his activities, and his growth. While this is not yet a burden he bears, it is certainly a burden his parents bear in order to take care of him and provide him the best support they can. **Continuing funding for research allows this family to move forward with vital ways for Grayson to grown and function in a world that does not easily cater to his needs. Funding for this is vital for so many families, not just ours!**



## ROSINA PROBASCO

### Easton, PA

I have secondary lymphedema from Synovial Sarcoma Cancer, which I had at the age of 17. They never thought I would make it, but I've survived the cancer (not once, but twice) and ended up with lymphedema for the rest of my life. Yes, I'm thankful for surviving a very low-rate-of-survival cancer. Unfortunately my life had completely changed with a deformed leg. As a teenager, then through my adult years, it has been a struggle every day. Not having the money to pay for essential compression garments that insurance does not cover. Going out in public trying to feel normal without people staring at you. Trying to find pants and shoes to fit. Bearing the pain with many sleepless nights. Being as cautious as possible not to get an infection, which leads to cellulitis and hospital stays. I could go on.

**Please, we need your help. If you or your loved one had this you would want to help them. Thank you!**

## MARY KAY RADNICH

### Meadville, PA

As a teenager, the first thing I noticed was that my hips were bigger than normal and my legs were shapeless. At 17, I sprained my right ankle and the swelling never resolved. Fast forward 37 years to age 54 and I was diagnosed with both primary lymphedema and lipoedema. My hips and legs are still disproportionately big. It is hard to buy clothing, and my compression garments are hot

and unsightly. I must always explain my ugly garments (stockings) and why my diseases never will go away. **Early diagnosis and treatment is KEY for management of both of these diseases—not a 37 year wait! Thank you.**

## EMILY SMITH

### Wynnewood, PA

Back in 2015 and after a year of being dismissed of my symptoms by my gynecologist it was determined that I had cervical cancer. Because it was found so late I had to undergo a radical hysterectomy which included removal of 60 lymph nodes. I was grateful to have been given a second chance and to be rid of cancer, but six months later while exercising I felt swelling in my left leg. As the days went on the swelling increased. I went to my doctor and was diagnosed with lymphedema. My leg no longer felt like it was a part of me, but instead felt like I was dragging luggage everywhere I went.

In 1996 I underwent another surgery to reroute my lymph nodes using my veins. This surgery has helped a lot, however I still need to wear compression garments every day, my leg needs to be wrapped every night before bed, and I have to make time to massage my leg daily. **To say the quality of my life has changed is an understatement. I will never take for granted all that our bodies are capable of. I do hope more services will become available and more research for a cure is something I will one day be fortunate enough to benefit from.**

***“Finishing my surgery for uterine cancer, I thought the worst was over. I would love to return to being a productive person rather than spending my life coping with lymphedema.”***

**KARI FORMSMA**  
Jenison, MI



## LISA VENUTO

### Coatesville, PA

I am 54 years old and have Stage 3 Lipedema with secondary lymphedema. I was just diagnosed a few years ago. I grew up all my life struggling with weight. I was always told that I ate too much and needed to exercise more. That was not true. I was always active and have been on a “diet” since the age of 12. If I had a diagnosis earlier on, I could have used wraps, leg pumps, dry brushing, MLD, etc., to help slow down the progression of my disease. I have just had both hips replaced (five years apart), and I believe this was due to carrying extra weight on my lower half.

I urge you to please help us get proper diagnosis, and help us to have access to qualified health providers. We also need to have insurance coverage of supplies. I spend \$300–\$400 every time I purchase my wraps. They are supposed to be replaced every six months. I stretch the time out to 8–10 months. Because of my condition, I no longer work, so it is a hardship for me to pay for them.

**Please help us to get this disease recognized and help us get proper treatment and supplies. Thank you**

## ERICA ZERVANOS

### Philadelphia, PA

**I was diagnosed with lymphedema when I was fourteen years old.** I came home from school one day, and my right thigh was significantly more swollen than my left thigh. I was an angry teenager who didn't want to believe I had injured lymphatics, so I refused to wear compression. All through my teenage years no one was able to tell me whether or not I had primary or secondary lymphedema. I always thought I had secondary because I was born with normal legs. It's been a never-ending journey trying to find answers. It wasn't until my twenties that I decided to just give up on trying to figure out why I have this but, rather, take care of it. I have had two liver transplants, and I struggle with chronic infection. Needless to say, my lymphatics have taken the front seat in regards to my chronic illness. I have carried around so much shame for ten years of my life because I felt like I was deformed. As soon as I was diagnosed, I threw out dresses and shorts. It's a burden that I carry every day. I wear compression stockings every day now, and I have a lymphatic pump, yet it's still not enough. **I walk around with the reality that there are no clear answers as to why I have this, and that there is no cure. It affects the way I feel everyday. It affects my mind and my overall quality of life. Please help people like me.**

## DANIELLE BELL

### Clinton, SC

18 years ago I had my first child. I spent the next ten years fighting swelling in my feet, ankles, and calves. I had leg infection after leg infection. It took a dual leg infection from toes to above my knees before I was referred to a vascular doctor who diagnosed me with bilateral lower leg lymphedema. I now wear compression stockings daily, but cannot afford a pump. Help is needed to find a cure for this debilitating disease. My leg tissues are starting to harden and I have to wear special thick garments over night to help break up the fibrosis.

**A cure in my time would allow me the freedom to enjoy more activities with my kids and future grandkids. I live in constant fear of a leg infection. Despite precautions, my last leg infection was in 2019, and I spent 21 days on antibiotics to clear it up.**

## LASHONN EDMUNDS

### Greenville, SC

I developed lymphedema 21 years ago after my third caesarean. The lymphatic disease caused my feet to swell so badly that I was unable to wear appropriate shoes in a corporate environment, which drastically changed my quality of life. I urge Congress to help our efforts in moving the lymphedema agenda to the forefront so that we can find a cure. No one should have to live like this and not be able to feel confident about themselves due to a disease. **I know there is a cure out there, and with the support of Congress I feel confident that we can find that cure soon.**

## WILL MILES

### CAYCE, SC

I am 23 years old and I was born with lymphedema. We traveled around to many different doctors looking for a diagnosis of why my ankle was swollen and never got one. While visiting my Grandma, her neighbor, a nurse, told us it looked like bilateral lymphedema. We finally had a name to call it. We soon began traveling again to find doctors and therapists who could give us information to help us understand my new diagnosis. The only one we could find that knew about lymphedema was a therapist an hour from my home. He gave us ways to help manage my lymphedema with compression garments and different machines.

**I love sports and played collegiate golf at the University of South Carolina. With my active lifestyle and constant traveling, it became harder to manage my lymphedema and keep a good**

***“It is simply not right that lymphedema is so under-recognized by the medical community, and that treatments and support are not covered by insurance companies.”***

**–Sarah McCollum, Portland, OR**

***“Until I was eight, I had lymphedema in only my right leg. I love to play soccer, but last year my other leg really swelled up and it hurt so much.”***

**NICHOLAS HERENANDEZ**  
Riverhead, NY

**quality of life.** I started experiencing numerous cellulitis infections in both legs. Fortunately, we found Dr. Dhruv Singhal in Boston to help alleviate some of the infections and size with a debulking procedure. While it isn't a cure, it is a step to get back to my active lifestyle.

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## **ANDREA ABERNATHY-BRIGGS** Collierville, TN

I acquired my lymphedema issues back in 2007 due to a slip and fall at my job. Over the years, I have had issues of swelling of my legs, back to back bacterial and viral infections, and osteoarthritis. I have done everything from leg wraps, pumps, and massages. But after ten years, I have no willpower to continue the treatments. Now I am in a nursing home/rehab center for my right knee that one of my doctors was concerned about when my walking was getting bad. But after being in a hospital before going to the nursing home, I lost 125 pounds of water weight and, unfortunately, the muscle strength in my legs and developed atrophy in my legs. I am doing exercises in bed and getting some of my leg strength back, but need a lift to get me out of bed and into a wheelchair. I have no infections at this time, but if I were to go back home and this coronavirus issue is still running rampant, I won't have anyone to help me in my time of need.

**If I ever get back to my normal life without lymphedema, I can work on my house, attend meetings with my convention group, shop for food, clothes, and supplies, and visit friends and family members. The dream is there but this struggle is forever real.**

## **NANCY CROSS** Memphis, TN

I've had lymphedema in my right leg from toes to hip since 2000. My swelling appeared soon after uterine cancer surgery and my life totally changed at that time. **All the doctors I saw about the swelling were either disinterested or unable to identify it as lymphedema.** As my condition progressed so did the pain and deformity. I also had to give up teaching, the profession I loved. It's bad enough for all of us to endure the pain, the activities we can no longer enjoy, the periodic and dangerous infections, the difficulty finding clothing to fit, etc. But to have to plead with insurance companies to help us with the cost of treatment and compression garments which will always be necessities, is extremely worrisome and unfair. **Please support us and help us find a cure from this cruel and debilitating condition.**

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## **NATHAN DUNN** Brentwood, TN

I'm 56 and was born with lymphatic problems. My lymphedema showed up in my left leg about 13 years ago. I went a short while without being diagnosed. Finally, after being released from a hospital stay due to cellulitis, my neighbor who worked for a hose company suggested. I had LE. I spent the first few years wearing hoses and getting treatment about once a year (it was too expensive to do more often). I then started wrapping from "toe-to-hip" for about six years, five days a week, to try to maintain the swelling. I finally found Dr. Granzow and was fortunate to go see him.



After over a year of fighting insurance and spending thousands of dollars just to try to get treatment, I finally got approved for surgery. My bill was over \$400,000!!! I'm forever grateful for getting to where I am but it should not be this hard!!

## JENNIFER FOSTER Johnson City, TN

I have lymphedema in both legs and feet. I was diagnosed in 2009. However, I have had lymphedema since 1998 due to a car accident. The front seat crushed my left leg and I had to have two surgeries and a skin graft. After that my left leg continued to swell, so much it was hard to even walk. The doctors I was seeing then told me to get checked for diabetes, which I did not have at the time.

**They could not figure out why my leg was swelling, so I just dealt with it until I could no longer work standing up and went to work at a call center where I could sit.**

I finally got insurance through my work and went to see Dr. Rebekah Cote, who immediately told me I had lymphedema and got me started with physical therapy and MLD at Blue Ridge Physical Therapy in Johnson City, TN. I was scared to death but they made me feel comfortable and I've been going there since. The only thing is now I'm disabled and my insurance (Medicare) only covers 80% of my therapy and nothing else. I can't afford the extra 20% so I can't go to physical therapy for my MLD and wrapping. I also can't afford my wraps and garments to keep it under control so I can have any kind of life outside my home. They covered the compression pump but without the wraps, garments, MLD, and physical therapy, there's no point in the pump.

## ANNETTE SCHMID Nashville, TN

I have been dealing with lymphedema for 17 years due to breast cancer and having lymph nodes removed. I've been in the hospital twice with cellulitis. The cost of lymphedema therapy, compression garments, and pump is so much money every year! Not to mention the pain you deal with every day. Swelling goes into my chest, trunk, and legs. **We need help! Please, Congress, do the right thing!**

## CHERYL SCOLEDGE Jackson, TN

**I've had lipedema at least since puberty, but was only diagnosed when I turned 50. How is it possible to be ignored for that long?**

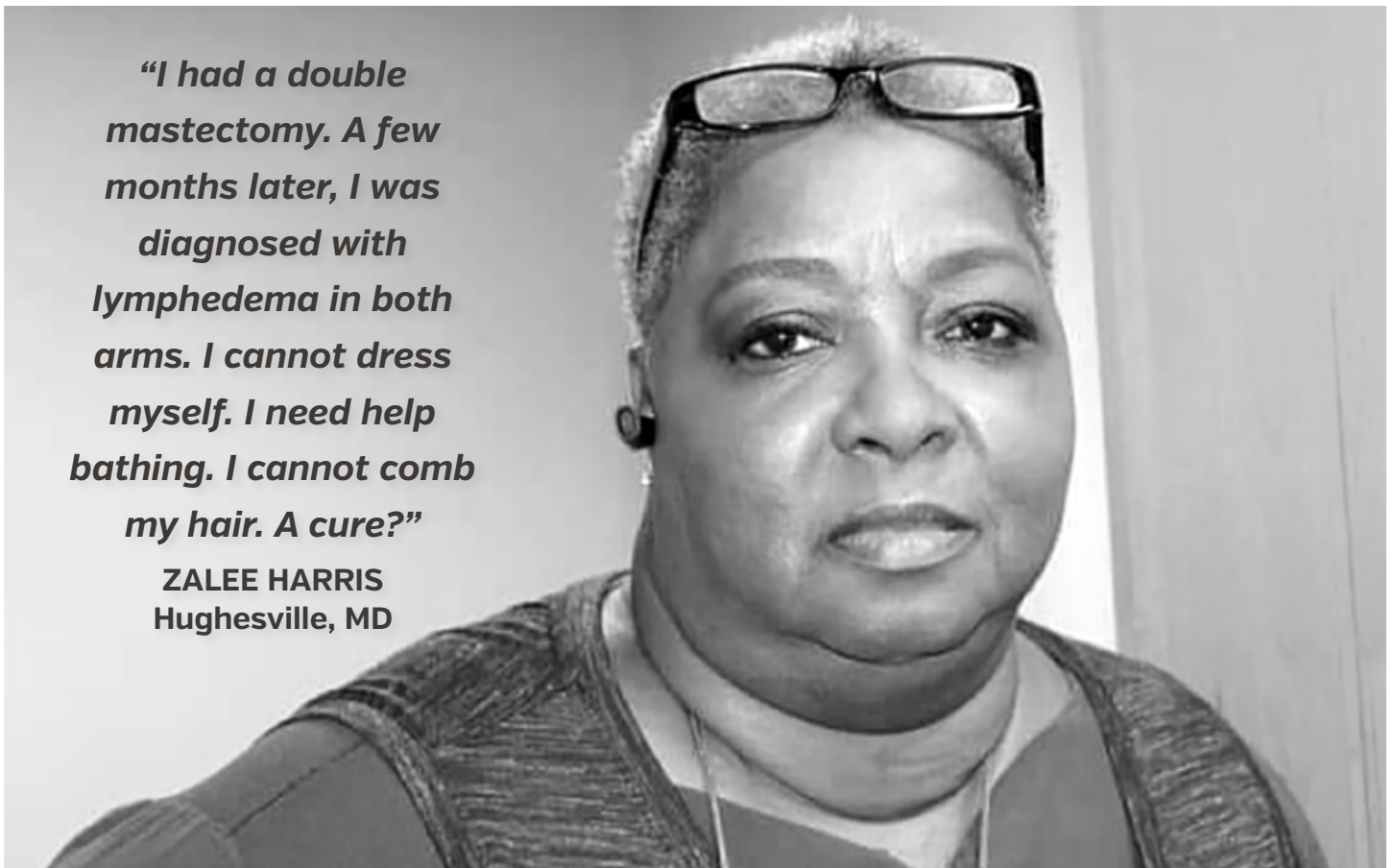
I typically spend 17–20 hours a day in bed, in order to keep my legs elevated, and my time out of bed is spent trying to maintain my health. Having my legs elevated in bed is a benefit for lipedema so that the lymph doesn't need to fight gravity.

It's been a blessing that I was able to create a job for myself at home. I can just "sit up" in bed and be at work. But, that also is an indication of how I've been able to hide my symptoms too. Bad day? Well, don't get out of bed, don't take a shower, don't get dressed. Just put on a good voice and answer the phone. And when it's REALLY bad don't answer the phone at all. Send an email when the issue is "fixed."

One of my favorite parts of my work life was meeting with customers and suppliers. I used to enjoy dressing as a professional.

***"I had a double mastectomy. A few months later, I was diagnosed with lymphedema in both arms. I cannot dress myself. I need help bathing. I cannot comb my hair. A cure?"***

**ZALEE HARRIS  
Hughesville, MD**



***“I was diagnosed with lymphedema when I was 14 years old. It affects the way I feel every day. It affects my mind and my overall quality of life. Please help people like me.”***

**—Erica Zervanos, Philadelphia, PA**

Since I am now limited in my ability to travel, carry items, or eat out with them, that part of my work life is forever behind me. **I have a difficult time giving up. This is why I need to share my story with you!**

## **ANA ALVARADO** **Forth Worth, TX**

In 2009 I was diagnosed with secondary lymphedema at age 21. I had a removal of a tumor in the right groin, chemotherapy, and radiation due to cancer diagnosis. Due to the tumor, my leg was swollen from the groin all the way down to my toes. The doctor who performed my surgery said the swelling would go away after a year. A year went by and the swelling never went away and, in fact, it was only getting worse. I visited a doctor at MD Anderson who diagnosed me with lymphedema.

Living with lymphedema is a day-to-day challenge. It has effected me physically and emotionally. I can not wear shorts, dresses, or skirts due to the swelling. There are days where I can't even cook because the pain in my leg is overbearing.

I am a mortgage processor and my job consists of sitting at a desk for eight hours. There are some days when I can't handle it. I'm afraid that one day I will have to quit my job. I do my best to care for myself, but sometimes it's never enough. Due to the social distancing taking place I have been working from home for three weeks now. **This morning I woke up with swelling in my ankle, something that is not normal for me. I am afraid this will become my new normal.**

## **CAM AYALA** **Houston, TX**

My name is Cam Ayala, and I am a 31-year-old hereditary lymphedema patient. I have been managing this chronic disease since I was 11 years old. I was born and raised in Houston, Texas, which has the largest medical center and some of the top physicians in the world. It still took over a year for me to get the proper diagnosis. **Lymphedema is not a one-size-fits-all disease. Though many patients experience similar symptoms, each patient has his or her own unique case which further validates the extreme necessity for increased research to better understand this unique disease that impacts over ten million Americans alone.**

Professionally, I am a compression therapy consultant for a company that manufactures pneumatic compression pumps for home therapy treatment. These are prescribed to patients who

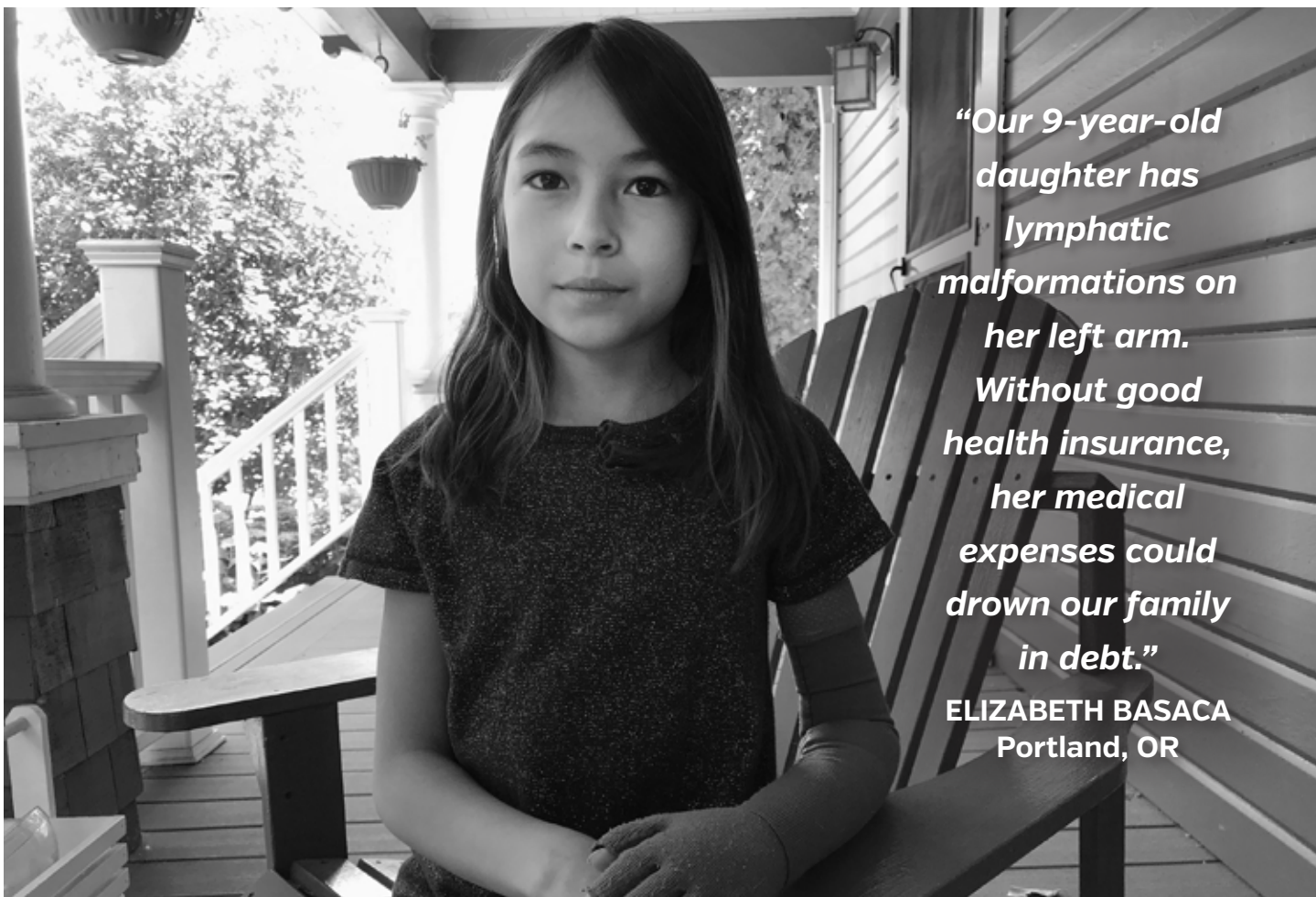
suffer with lymphedema and other chronic swelling conditions for which there is no current cure for. **Day in and day out I experience patients being denied the care that they need due to lack of a physician diagnosing accurately and a severe lack of insurance coverage for necessary treatment.** We are also better understanding the genetic components of lymphedema, which means there is a strong likelihood that my future children could inherit this chronic disease. **I encourage you to hear our cries and to prioritize funds that are extremely needed to facilitate research and education for a cure!**

## **JOY BARNETT** **Kingwood, TX**

When I was diagnosed with lipedema and secondary lymphedema, or lipolymphedema, I was devastated. At the time I was 54 years old, but I had actually had this condition for years. **Now it had a name. And no cure. And would be progressive. For the rest of my life.** We are told to be thankful that it is manageable, and I am, but management is time-consuming and expensive. I would rather not go to a licensed lymphedema therapist every day for two months once a year to be massaged and wrapped with bandages to wear all day and night to reduce swelling. I would rather not spend two hours a day lying in bed using a pump to simulate manual massage. I would rather not have to wear compression garments 23 hours a day. I would rather not have to worry about whether I can walk on any given day because my legs are too swollen and heavy. **All of the people suffering from lymphatic diseases ask for one thing—a cure. Please help us.**

## **ZACHARY BERGER** **Conroe, TX**

I am a 16-year-old sophomore in Texas. **The impact lymphatic malformation has had on my life is dramatic, because it not only has impacted me, but my family as well.** I was born with macrocystic and microcystic cysts in my neck, jaw, and tongue. I have had eight surgeries including a tongue reduction surgery where they cut seven millimeters out of the middle of my tongue and sewed the two sides back together. I also had some of the tip of my tongue removed. I continue to experience tongue swellings randomly. In fact, as I write this, I am swollen and in pain. **There is no cure and it is hard not to be very mad and frustrated that there is currently NO MONEY being put toward research for a cure for lymphatic malformations. Lymphatic malformation also effects my education, my social life, and my emotional state.**



***“Our 9-year-old daughter has lymphatic malformations on her left arm. Without good health insurance, her medical expenses could drown our family in debt.”***

**ELIZABETH BASACA  
Portland, OR**

A cure would mean the world to me and to the thousands that suffer from lymphatic malformation and lymphatic disease. We are a large community with nowhere to turn. **I would literally do just about anything to help find a cure. I am trying desperately to raise awareness and research money.**

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## **STACY DODSON** **Frisco, TX**

I am 46 years old and recently diagnosed with lymphedema and lipedema. It has taken me a year or so to find out what the mass was on my legs. The issue was 1) Finding a doctor who was knowledgeable about the diseases; and 2) Finding a doctor and therapist who was in network. The first doctor was an Ortho and she said the mass was inflammation caused by my knee. She gave me a steroid shot and prescribed physical therapy. At the end of the therapy they advised it was not my knee but could be lymphedema and referred me to another Ortho who they thought might be knowledgeable but, nope, he wasn't. **It has been mentally draining and I have cried many days and at one point gave up because I felt defeated.**

I had to enlist the help of Cigna to try and find a provider because lymphedema did not show on their website. The representative recommended I see a vascular doctor and provided me a list. At TX Vascular Associates they would not schedule an appointment

unless I had a diagnosis. I did a Google search and found an OT by the name of Rebecca Summers. She was out-of-network but I decided to pay the out-of-pocket cost up front for a consultation. She was very patient and thorough and she diagnosed me with Lipedema. I called TX Vascular back and they had none of my info (referral, medical records) on file and did not specialize in the disease. I now have OT, a vascular doctor, and a surgeon.

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## **KATY JONES** **Fort Worth, TX**

Surviving non-Hodgkin's lymphoma twice has come at a price. Chemo and surgery to remove lymph nodes for biopsy have permanently damaged my entire lymphatic system. **My new 24/7 job is managing lymphedema. Doctors, lawmakers, and insurance companies need to know how REAL and devastating LE is!**

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## **KATHY PHILLIPS** **Bulverde, TX**

I have neck lymphedema secondary to throat cancer diagnosed in 2019. What a shock it was to learn that the pump which would help manage it is not covered by Medicare! If only I had been diagnosed with lymphedema one month earlier when I had private insurance



through my employer it would have been covered. In my job I worked daily with lymphedema patients, never dreaming I would be one. It is a life-changing diagnosis and is always with you. **There needs to be more funding for research and more education for physicians and medical students so early diagnosis can be achieved. I was lucky to have a physician that recognized I was in the early stages.**

## GAY RESTER

### Arlington, TX

I'm 61 and was diagnosed in 2014 with stage 3 inflammatory breast cancer. That has now metastasized to my right hip bone, making it stage 4 cancer. To attempt to get rid of it, I had two unsuccessful lumpectomies, then a right mastectomy, Chemo and radiation. Then it spread to my left lymph nodes a year later so I had a left mastectomy, more chemo, and radiation. I feel very lucky to still be alive in 2020. Now, if only a magic pill could be discovered to reduce the lymphedema in my right arm that spreads to my shoulder and neck and sometimes left arm too. Even morphine can't ease the pain of lymphedema when it flares into deadly cellulitis from time to time, requiring antibiotics and steroids that have consequences as well. **Please, please address lymphedema to find a cure. Or at the very least cover therapy and methods to somewhat relieve it and prevent the deadly cellulitis it can lead to! (Thank you to Kathy Bates for turning a negative lymphedema experience into such a positive hope for so many of us struggling and suffering in silence with this!)**

## VERONICA SENERIZ

### Katy, TX

I was born with a form of genetic lymphedema called Lymphedema-Distichiasis Syndrome, which presented in 1994 in one leg, but eventually spread to both legs (bilateral lower extremities). Although I was aware that I was primary, I did not know about being this specific type and the connection between my eyelashes and my legs. I'm 45 years old and developed it at age 20, which means I've lived over half my life with this disease with little to no support. It is physically and emotionally painful.

**I am third generation in my family to have this incurable condition. My grandfather was also bilateral like me. I also have an uncle and two first cousins currently living with lymphedema. LE has run in my family for over 115 years. All of us are native Texans.**

My blog, *Lymphie Strong*, was created in 2015, and is dedicated to my father, Pete, who lived with lymphedema of his left leg since the early 1970s. He was the strongest person living with it that I personally knew, and a hero in my daily fight against lymphedema. He lived with LE for over four decades with the first 24 years being completely misdiagnosed, untreated, and enduring over 100 bouts of cellulitis.

Sadly, my father passed away in June 2016 from cancer. While I am devastated at losing him, I am comforted that part of his legacy will live on in helping others with lymphedema.



*"I am told there is no cure for lymphedema (LE). I don't believe that. I acted full-time for 30 years. With LE that all ended."*

**KATHLEEN MULLIGAN**  
Wilmington, DE

***"I am the third generation in my family to have this incurable disease. My grandfather was also bilateral like me. I also have an uncle and two first cousins living with lymphedema. LE has run in my family for over 115 years."***

**—Veronica Seneriz, Katy, TX**

## **LESLIE ZACHARY** **Austin, TX**

In May 2013 I was diagnosed with endometrial cancer at age 57. I had a complete hysterectomy and removal of 40 pelvic lymph nodes. The nodes were all clean.

By October 2013 I was diagnosed with lymphedema in both legs and torso. I wear compression garments day and night, 23/7, exercise twice daily, do self massage daily, and require professional lymphatic massage twice a week to manage the swelling. In 2018 the lymphedema spread to my left arm. I am still working full time at age 64 and I don't see retirement anywhere in sight. My expenses for garments and therapy run \$25,000 a year. My insurance covers some of the cost of garments, but in a year when I go on Medicare, without private insurance the entire cost of these expenses is mine. A cure for lymphedema, a progressive, chronic disease would change my life. I live in fear of not being able to afford the garments and therapy required to slow its progression.

**Millions of peoples' lives would be transformed with a cure, and access to compression and good medical care for management of lymphedema would save hundreds of millions of dollars. Please vote for legislation to help find a cure for this heartbreaking disease.**

## **ANNA HAMBLIN** **Hyrum, UT**

I was diagnosed with lymphedema after Stage 3 breast cancer and removal of several lymph nodes. It has been 11 years of dealing with the health care system to receive needed garments and treatment throughout the years. About five years ago I found a lymph therapist who also diagnosed lipedema in both legs. **The compression garments are expensive and with insurance allowances of only two garments every six months, I have to decide which garments I need most. Legs and arms should not be grouped together!** This forces me to choose and leaves me with decreased maintenance and increased potential health problems.

## **IZZY SNYDER** **Guilford, VT**

Lymphedema causes me some amount of pain most days and limits the amount of time I can stand up. It makes me worry about my future and about passing down my genes to children if I have them.

It made me go through a horrible and traumatic diagnosis process with an ill-informed doctor, and it makes me wear uncomfortable compression garments for 16 hours a day. A cure for lymphedema would be amazing.

**Lymphedema is a financial, physical, and emotional burden on so many people. There is so little research into this disease, and treatments have barely changed since it was first discovered. It is time to invest in the research we need to cure lymphedema.**

## **DOLORES GOMEZ-REY** **Hampton, VA**

Seven years ago the swelling in my feet stopped going down. I noticed a small water blister on my ankle and thought it was an ant bite. Two days later it burst but, instead of healing, my whole leg from the kneecap down was soon open as if it had road rash. The burning was horrible! It traveled to my other leg and water would leave puddles wherever I sat or stood. I finally went to the ER where I was hospitalized for five days and put on six IV antibiotics. With my legs wrapped to heal I was sent home in bound hospice and wrapped my legs all summer.

**Did I mention I was seeing a doctor the WHOLE time who would say, "Yup, thats swollen!"** I was a hairdresser. I've been homebound for five years now. I can't stand up straight as lymphedema is in my entire body. My spine has been strained from water weight. The pain is unbearable but I deal every day with it. I'm 60 and used to be active. Now, not so much. Please, please help. It's a crippling disease, especially when doctors know nothing about it. I want to live before I die, just walk upright. **I can handle pain but I can't handle not having hope!**

## **CHRISSY LOWE** **South Chesterfield, VA**

I personally know and love a child affected by lymphedema and have seen the stress that this condition has placed on his family and loved ones. Without certainty of medical treatment or financial support, this leaves families in a vulnerable situation where they are trying to manage care, advocate for the child, and assume the financial burden of unpredictable expenses. **The hope of a cure would mean the world to those who live with this disease daily.**



*“Growing up, the hospital felt like my second home. I’m concerned about the future because there’s no cure for my disease.”*

**HANNAH WALSH**  
**[With her father, Tim]**  
**St. Petersburg, FL**

## **MAUREEN NOFTSINGER**

### **Salem, VA**

When I was 39 years old I was in the best shape of my life. I was an active, competitive triathlete living my best life with my husband and two young children. Suddenly and unexpectedly the course of my life changed. I was diagnosed with cervical adenocarcinoma (Stage 2B) and had a radical hysterectomy. **I developed lymphedema immediately but it was never diagnosed until a year later.** The physical changes, cellulitis, and emotional trauma have taken a toll on me both personally and professionally. My life included a divorce, PTSD, manual lymphatic drainage, and use of a pump. Taking care of my leg and my health has become a full-time job. As well as thousands of dollars spent on garments to help control it that are not covered by insurance. Yet I feel blessed and am extremely grateful to be able to afford them. The pain is a reminder of the trauma on a daily basis. **Caring for lymphedema as we age does not get easier, rather it becomes more challenging. We need focused research to find a better way to detect the spread of cancer that doesn’t have life-altering, forever consequences or a way to cure this disease.**

## **DIANE RUSSELL**

### **The Plains, VA**

In 2013 at age 46, a partial hysterectomy (because of a fibroid) revealed an early grade endometrial cancer. Having both fallopian tubes and ovaries removed, with a lymph node dissection two weeks later, revealed that my early grade cancer—which never should have spread—did spread to both ovaries and one lymph

node. Diagnosed with Stage III endometrial cancer, I had six cycles of chemo followed by daily radiation treatments lasting six months. **As a registered mammographer, and my husband a radiologist, we were concerned about lymphedema (LE). My oncology surgeon, who retired shortly after my surgery, repeatedly said I would not be affected.** During a follow-up appointment with my new oncology surgeon four months later, I was diagnosed with secondary lymphedema of my right leg. I was fortunate to find a local physical therapist specializing in LE, and did everything prescribed: barbaric leg wrapping, weekly PT appointments for manual lymph drainage which didn’t help, and wearing compression garments all day every day. Insurance coverage was minimal. Unable to ever work again, with my entire right leg, buttocks and abdomen swollen, and unable to find clothes or shoes to wear, I became reclusive. I eventually purchased an extremely expensive lymphatic pump to use daily, even when traveling, in addition to wearing compression garments for the rest of my life. **LE is worse than a cancer diagnosis or treatment.**

## **ESTEBAN DELGADO**

### **Renton, WA**

I have advanced lymphedema (LE) that went undiagnosed and untreated for at least 25 years. Sadly, that’s very typical, as most doctors know almost nothing about this condition. Because it was untreated, the LE has spread all over my body. I’ve been in hospitals and nursing homes for six years now. All of this could have been prevented had my doctors known more about LE.



## HEATHER MACLAUGHLIN GARBS Seattle, WA

As an active and athletic person, I had noticed a few times that my feet were starting to swell after a long run or hard workout. Then it started happening more and more and there was more intense pain associated with it. Finally, my feet and legs would swell and hurt during a regular day, not just after a workout or long event. I was finally diagnosed with primary lymphedema at age 38 when I went to a physical therapist for a curling injury to my ankle and she said she could help with that. But I also needed extensive wrapping and manual lymph drainage for my lymphedema. I had no idea that was what I had until she diagnosed it! I had always had larger legs and no matter how much I exercised, they didn't get smaller.

**A cure would mean I could go back to exercising and being active like I have been in the past and less (or hopefully no) pain during long events when I have to stand.** It would also boost my self-confidence a considerable amount so I don't have to hide under long pants and skirts anymore and can wear normal shoes!

## CAROL VOJIR Lynnwood, WA

It all began after age 70! It's bicycling related, more's the pity. After one ride of 35 miles, I noticed fairly severe swelling in my groin area, which interfered with urination. That has happened every time since after biking. I had no idea what the problem was!! People laughed at the idea of a fat groin, and I did too! **My physicians didn't have a clue.** Because I moved to Seattle in 2017, I haven't been biking as frequently so it hasn't been as much of an issue. But now? I want to bike more but I also want a better aftermath!! I need the exercise. Fortunately, I have an injury massage therapist, who helps. I also will try a compression garment specific for bicycling as well as lowering my saddle an inch. Stay tuned. I'd like to turn into a success story!

## DEANNA WILSON Veradale, WA

My daughter, Amanda, got lymphedema in both legs, from a cut that the emergency room didn't treat properly. It has caused such pain and a huge play in her emotions. She is a wreck! **A younger, vibrant, hard working gal now ready to go insane and on anxiety and depression meds!**

She lost her job as can hardly walk at times. State insurance won't pay for the physical therapists that she needs to work with to understand lymphedema and learn what to do to ease the pain. Amanda applied for disability, but that can take a very long time she was told.

**Experts state that there is no other disease affecting Americans so much and yet receives so little attention. Washington state doesn't even recognize March 6th, which is World Lymphedema Day!**

## KATHY SEDAN Egg Harbor, WI

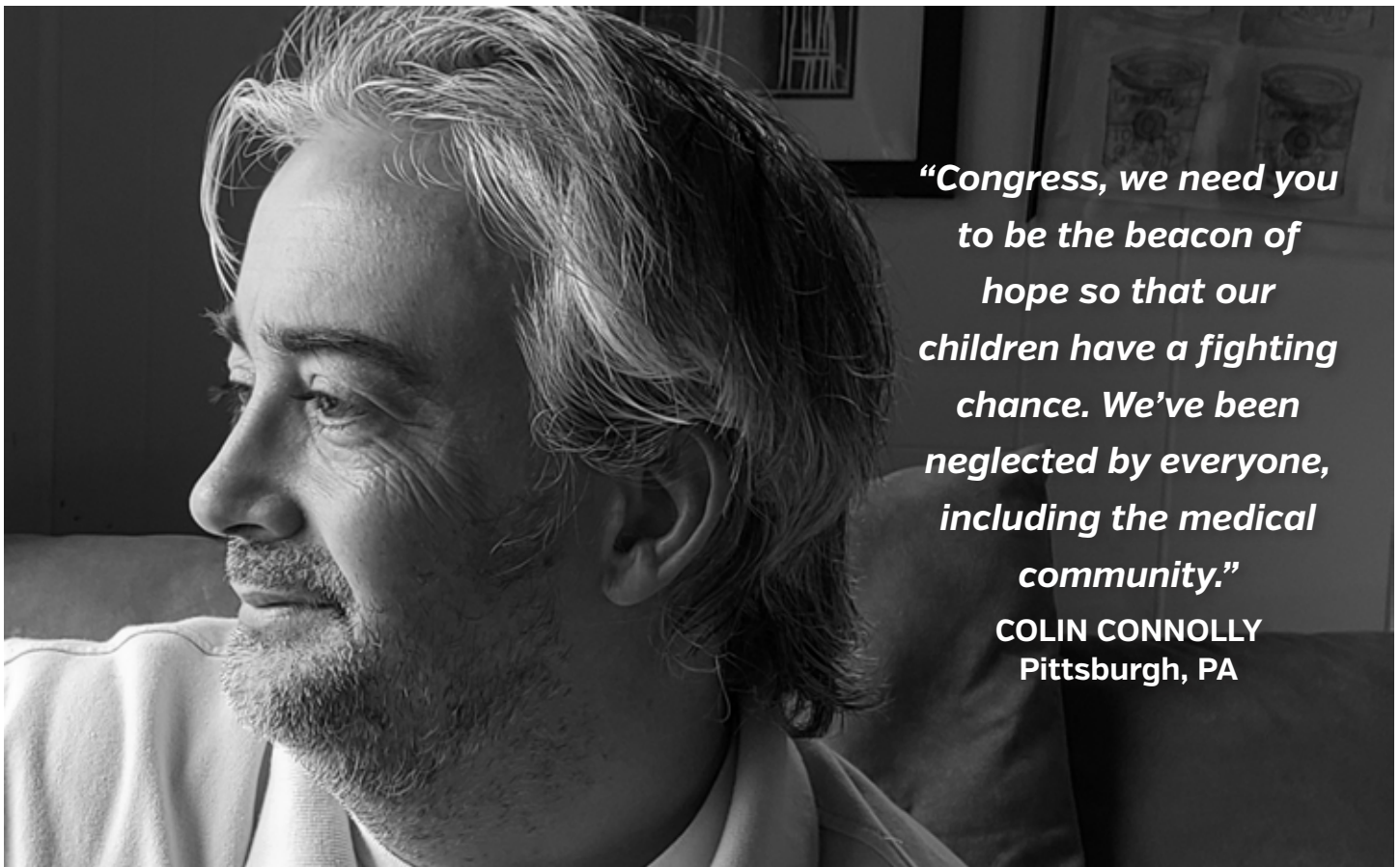
My lymphedema began in February 1971 with swelling in my left foot. **It took many years, many misdiagnoses and many trips to many doctors to be properly diagnosed.** When it was finally diagnosed, the doctor told me "Well, the dice rolled and you got it." One vascular doctor told me I would never be able to bear children as the pressure would be too great; that if I became pregnant, my legs would have to be amputated so at the age of 25, I had an irreversible tubal ligation.

Now, 49 years later, the lymphedema has spread to both legs and up into my torso, stretching almost to my rib cage.

**It is my fervent hope and prayer that no other lymphedema sufferer would ever have to experience the things I have experienced. That with better educated and trained doctors, more dedicated lymphedema therapists, better awareness and better research, lymphedema—especially my primary lymphedema which no one can tell me what causes it—would and could be cured. Thank you.**

***"It is my fervent hope and prayer that no other lymphedema sufferer would ever have to experience the things I have experienced."***

**—Kathy Sedan, Egg Harbor, WI**



***“Congress, we need you to be the beacon of hope so that our children have a fighting chance. We’ve been neglected by everyone, including the medical community.”***

**COLIN CONNOLLY**  
Pittsburgh, PA

## **JOAN SOKOLOWICZ**

### **Greendale, WI**

My lymphedema story began in 1997 when my right leg started swelling for no apparent reason. I didn’t know that I had lymphedema, but I was finally diagnosed in 2011. I stopped wearing dresses, skirts, shorts, or capris. My compression stockings are no longer covered by my medical plan and Medicare will not cover anything associated with this disease. **I wouldn’t wish this on anyone. The worst thing is the isolation. No one understands what I am going through and even my friends don’t really understand. It is very lonely having lymphedema. I am one of eight siblings but the only one with this.**

## **LINDSEY SOSOVEC**

### **Jackson, WY**

**No one warned me about lymphedema. No one told me it could happen to me. I honestly didn’t even know the definition of lymphedema.**

While celebrating my birthday in the Guadalupe canyon outside of Tacate, Mexico, my right leg began to swell. Assuming I was bit by a bug, or had a strange reaction to something, I continued exploring, jumping off waterfalls and canyoneering. As I left the canyon for the U.S. border, my leg elevated on the dashboard of the rental van, I realized my next stop needed to be the emergency room.

Knowing my medical history (including cancer, a radical hysterectomy and lymph node removal) the ER doc cleared me to leave the hospital and cleared me to fly to Indonesia. The doctor physically checked off a box that said I was negative for lymphedema. Little did I know my life and body would never be the same again.

My journey, two years and tens of thousands of dollars later, most not covered by my BCBS insurance, has led me to advocacy and education within the lymphedema world. I am an ambassador for Juzo, a leader in medical grade compression. I’m also collaborating on projects and patents to make our lymphedema lives easier.

**I’m asking my home state, Wyoming, the state where I grew up and currently live, to help. Please move this forward!**



Lymphatic Education  
& Research Network

261 Madison Avenue, 9th Floor | New York, NY 10016

April 1, 2020

The Honorable Rosa DeLauro  
Chairwoman  
Subcommittee on Labor, Health and Human  
Services, Education, and Related Agencies  
U.S. Senate Committee on Appropriations  
2413 Rayburn House Office Building  
Washington, DC 20515

The Honorable Tom Cole  
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U.S. Senate Committee on Appropriations  
2207 Rayburn House Office Building  
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The Honorable Roy Blunt  
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U.S. Senate Committee on Appropriations  
260 Russell Senate Office Building  
Washington, DC 20510

The Honorable Patty Murray  
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U.S. Senate Committee on Appropriations  
154 Russell Senate Office Building  
Washington, DC 20510

RE: National Commission on Lymphatic Diseases Research

Dear Chairwoman DeLauro, Chairman Blunt and Ranking Members Durbin and Murray:

Thank you for your leadership on funding for medical research and support of the lymphatic disease community by including specific recommendations in the FY 2020 LHHS Appropriations Bill encouraging NIH to create a National Commission on Lymphatic Diseases:

*“National Commission on Lymphatic Diseases.—OD and NHLBI are applauded for facilitating the 2015 Trans- NIH Lymphatics Symposium. Lymphatics research has the scientific potential to treat a variety of severe diseases, including heart disease, diabetes, rheumatoid arthritis, and cancer. The Director is encouraged to establish a National Commission on Lymphatic Diseases or other appropriate mechanism to explore and make recommendations on the ongoing expansion and coordination of lymphatic diseases research NIH-wide.”*

We have followed up with NIH, specifically with the NIH Director’s Office about how LE&RN can assist and partner with NIH in taking the important next steps that will lead to meaningful progress to establish the Commission. To date, the response has been to refer us to National Heart, Lung, and Blood Institute. Despite NHLBI’s genuine support of our agenda, only decisive action by the Director’s Office will move us beyond the status quo of lymphatic disease research.

The scientific community researching lymphatic diseases is eager to embark on this important process to reinvigorate the NIH research portfolio and define a path forward for progress in this challenging area of study. The status quo limits the opportunity for progress, and we firmly believe now is the time to create this Commission that would explore and create recommendations that would expand and better coordinate lymphatic diseases research across NIH.

We ask that you continue to support the establishment of the National Commission on Lymphatic Diseases and intervene with NIH as necessary. There is much work to be done in researching lymphatic diseases. Breakthroughs



## Appendix A: National Commission Support Letter

will only happen by establishing the Commission to thoroughly examine the portfolio and make recommendations on how best to advance this emerging scientific area under NIH's current structure.

Thank you for your time and consideration of this request.

Sincerely,

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## Appendix A: National Commission Support Letter

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## Appendix A: National Commission Support Letter

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## Appendix A: National Commission Support Letter

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## Appendix B: Research Funding Support Letter



Lymphatic Education  
& Research Network

261 Madison Avenue, 9th Floor | New York, NY 10016

June 4, 2019

The Honorable Richard Shelby  
Chairman  
Subcommittee on Defense  
U.S. Senate Committee on Appropriations  
304 Russell Senate Office Building  
Washington, DC 20510

The Honorable Richard Durbin  
Ranking Member  
Subcommittee on Defense  
U.S. Senate Committee on Appropriations  
711 Hart Senate Office Building  
Washington, DC 2051

The Honorable Roy Blunt  
Chairman  
Subcommittee on Labor, Health and Human  
Services, Education, and Related Agencies  
U.S. Senate Committee on Appropriations  
260 Russell Senate Office Building  
Washington, DC 20510

The Honorable Patty Murray  
Ranking Member  
Subcommittee on Labor, Health and Human  
Services, Education, and Related Agencies  
U.S. Senate Committee on Appropriations  
154 Russell Senate Office Building  
Washington, DC 20510

Dear Chairmen Shelby and Blunt and Ranking Members Durbin and Murray:

Thank you for your leadership on funding for medical research. On behalf of the lymphatic disease medical research community, we ask that you increase funding and improve coordination on lymphatic disease research, as you work to complete the Senate's Labor Health and Human Services (LHHS) and Defense appropriations bills for fiscal year (FY) 2020.

Millions of Americans suffer from lymphatic diseases such as lymphedema and lipedema. Lymphatic diseases are associated with a diminished quality of life (QOL) and life-threatening infections. Cancer patients who develop lymphedema incur twice the cost in medical expenses as opposed to survivors who do not develop lymphedema. Treatments are limited, and there is no cure.

Current lymphatic research is leading to clinical applications in the treatment of lymphedema. It is also poised to make a monumental impact on the continuum of lymphatic diseases which includes obesity, diabetes, heart disease, AIDS, Rheumatoid arthritis and cancer metastasis. Recent discoveries point to the potential impact of lymphatic research on Alzheimer's disease and multiple sclerosis. Success in finding breakthroughs to treat and cure these diseases is inexorably tied to the level of funding investment in this research.

We request your support for expanding and advancing the lymphatic disease research portfolio at the NIH. Further, please also include "lymphatic diseases" as a category eligible for study through the Department of Defense's Peer-Reviewed Medical Research Program (PRMRP). Lymphatic diseases disproportionately affect active duty service members and first responders, as they often arise from trauma, bacterial infections and as complications of cancer treatment.

## Appendix B: Research Funding Support Letter

Thank you for your time and consideration of this request.

Sincerely,

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## Appendix B: Research Funding Support Letter

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## Appendix B: Research Funding Support Letter

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## *Appendix B: Research Funding Support Letter*

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**Yokohama City University**  
**Yokohama, Japan**





Lymphatic Education  
& Research Network

261 Madison Avenue, 9th Floor | New York, NY 10016

March 25, 2019

The Honorable Richard Shelby  
Chairman  
Subcommittee on Defense  
U.S. Senate Committee on Appropriations  
304 Russell Senate Office Building  
Washington, DC 20510

The Honorable Richard Durbin  
Ranking Member  
Subcommittee on Defense  
U.S. Senate Committee on Appropriations  
711 Hart Senate Office Building  
Washington, DC 20510

The Honorable Roy Blunt  
Chairman  
Subcommittee on Labor, Health and  
Human Services, Education, and Related  
Agencies  
U.S. Senate Committee on Appropriations  
260 Russell Senate Office Building  
Washington, DC 20510

The Honorable Patty Murray  
Ranking Member  
Subcommittee on Labor, Health and  
Human Services, Education, and Related  
Agencies  
U.S. Senate Committee on Appropriations  
154 Russell Senate Office Building  
Washington, DC 20510

Dear Chairmen Shelby and Blunt and Ranking Members Durbin and Murray:

Thank you for your sustained commitment to medical research. As surgeons who specialize in the treatment and prevention of lymphatic diseases such as lymphedema and lipedema, we hereby state our unwavering support for further collaboration and coordination on important research in this area.

In brief, millions of Americans suffer from lymphatic diseases such as lymphedema and lipedema. Lymphatic disorders are associated with a diminished quality of life (QOL), life-threatening infections, and cancer patients who develop lymphedema incur twice the cost in medical expenses as opposed to survivors who do not develop lymphedema. There is no cure.

Current research demonstrates that employing new surgical techniques could significantly reduce the incidence of lymphedema onset in patients undergoing cancer treatment. We need NIH to fund basic research with clinical implications for lymphatic diseases to help guide our surgical approaches.

In summary, we request your support for expanding and advancing the lymphatic disease research portfolio at the NIH. Further, please include “lymphatic diseases” as a category eligible for study through the Department of Defense's Peer-Reviewed Medical Research Program.

## Appendix C: Surgeons Research Funding Support Letter

Thank you for your consideration of this request.

Sincerely,

**American Society for Reconstructive  
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Chicago, IL 60602**

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