



Wellness Update

**I Have
Lymphedema
and I'm
Mad as Hell**

***TIME
FOR BED!***

*Fat, Salt and
Sugar Can Be
Good For You?*

SOME GOOD NEWS
ON OPIOID EPIDEMIC



I HAVE LYMPHEDEMA AND I'M MAD AS HELL

Who can forget the “sweet” psychopathic Annie Wilkes nursing her favorite author back to health and bringing Misery back to life? Or maybe it was the timid housewife, Evelyn Couch that had you secretly cheering as she stood up to the parking lot bullies. Better yet, the sometimes vulgar, but passionate “Unsinkable Molly Brown” who commandeered a lifeboat full of women from a quartermaster on the Titanic. Regardless of who may be your favorite, these women have one force in common — Kathy Bates. A force to be reckoned with in her own right, Kathy Bates has been known as a tough fighter.

Professionally she fought, overcoming an industry full of stereotypes and doubters — and she came out on top. Achieving success much later in life than some has not stopped her drive and ambition to be the best she can be. Even the personal battles in her life did not slow her down. Kathy has battled cancer — twice. A diagnosis of ovarian cancer in 2003 followed by breast cancer in 2014 was met with her fighting spirit. A double mastectomy was the best course of action to take care of the breast cancer.

But now she battles a new foe. Lymphedema.

Throughout her life, Kathy Bates has been no stranger to cancer. Her mother, aunt, niece and a close friend had their own battles. It wasn't until her own double mastectomy that she was able to connect the dots to the disease of lymphedema. She had noticed side effects of the cancer treatments in those close to her, but didn't really know what it was, other than it was 'no way to live'.

Almost immediately after her surgery, she began to feel the effects of lymphedema. "It felt like a lightning storm of pain" Kathy recalls, "it moved around in different places." Most doctors have little experience with lymphedema. "My surgeon knew it was a possibility, but the statistics on how many women develop lymphedema vary from 30 percent to 60 percent. My surgeon's focus was on curing me of cancer which is as it should be. Especially since the lymphatic system is the highway that cancer cells use to metastasize other parts of the body," she said. Battling cancer is no easy task, and few know lymphedema is the nature of cancer.

In addition to both breasts, her doctor removed 19 lymph nodes on her left side, and 3 from the right. While not all cancer patients develop lymphedema immediately after cancer treatments, Kathy considers herself lucky to have what she considers

WHAT IS LYMPHEDEMA?

Lymphedema is swelling that occurs usually in one of your arms or legs. Sometimes it can occur in both legs or both arms. It can develop due to radiation, surgery, infection or trauma. Lymphedema most commonly occurs in women due to the removal of or damage to the lymph nodes as part of breast cancer treatment.

The lymphatic system is part of the immune system. It helps the body fight infections. It also helps maintain fluid balance in different parts of the body. It is made of a series of thin tubes, called lymphatic vessels. These vessels collect fluid, called lymph, from different parts of the body. Similar to blood vessels, these vessels then carry the lymph back to the bloodstream. Lymph is a colorless, watery fluid that is rich in white blood cells called lymphocytes. These cells play an important role in the immune system by protecting your body against infection. Lymphocytes form and are stored in lymph nodes, which are pea-sized collections of cells located throughout the body, such as in the armpit, groin, and neck area.

There are two types of lymphedema:

- PRIMARY — occurs on its own
- SECONDARY — caused by another disease or condition



Kathy with William Repicci, Executive Director LE&RN

mild symptoms. Her daily routine involves compression sleeves, and avoiding activities that might cause her arms to swell. Simple things that start with watching salt intake, alcohol, sitting for long periods of time, even a hot bath, all have effects on her lymphedema.

Getting lymphedema “felt like a punishment for having cancer”. When asked why, after all she’s been through with cancer, she didn’t just curl up in a corner and give up, she simply replied — “I was pissed off!” Perhaps that feisty Irish frame of mind helped when she was introduced to Bill Repicci, Executive Director at Lymphatic Education & Research Network (LE&RN). In her journey of lymphedema, one very large common denominator she noticed was the lack of awareness in the medical community. So, when LE&RN asked her to be a spokesperson, she felt like she was finally able to say for the first time in 60 something years “Yeah, I really care about this! I’m going to give it a go!”

The motivation — seeing the injustice of this disease. Kathy Bates may have won her battles with cancer, but the war still rages on. Not just for her, but for millions more. An estimated 10 million Americans suffer from this devastating disease. That’s more than Multiple Sclerosis, ALS (Lou Gehrig’s Disease), AIDS and Parkinson’s combined. The more people Kathy met who were suffering, the more passionate she became.

WHAT ARE THE SYMPTOMS OF LYMPHEDEMA?

Lymphedema symptoms include:

- Swelling of your arm or leg along with fingers or toes
- A feeling of heaviness or tightness
- Aching or discomfort
- Reduced range of motion
- Persisting infections
- Thickening and hardening of skin (fibrosis)

The swelling caused by lymphedema can range from mild or hardly noticeable changes in the size of your leg or arm to extreme changes that make the limb difficult and painful to move. Lymphedema caused by cancer treatment may not appear until weeks, months or years after treatment.



Marie Apodaca finishing first ever 5K

"I spend 90 percent of my time pretending to be other people and getting paid nicely for it, but what was so exciting for me was to be spokesperson for this group." Kathy says, "I'm doing something real — it's in the real world and hopefully it can help real people. I don't know where it will go — but I have dreams."

When asked of her inspiration to continue giving a voice to this often misunderstood disease, she immediately credits all those she has met. She is in awe when she sees that once these patients, much like her, get



Kathy walking with a participant



Pearl-Ann Hinds doesn't let lymphedema stop her from dancing

past the shock and anger...move forward and find a positive way to deal with this so the disease "doesn't define them".

It's not hard to feel Kathy's passion as she speaks about those who aren't defined by lymphedema. They come from all walks of life, young and old. Sharing a need to be heard and understood, looking for answers that are too often pushed aside and ignored.

There's Marie Apodaca, who unknowingly lived with lymphedema because she was not properly diagnosed. After almost losing her left leg to gangrene due to her untreated condition, she knew she had to be an advocate for herself. Anger set in as she began to educate herself on lymphedema. "Something amazing happens when you get angry doesn't it? It can light a fire in you that you never knew was there to be lit." She

There is no cure for lymphedema. A treatment plan, focusing on reducing swelling and controlling pain, should be based on evaluation by certified lymphatic therapist. It may include one or more of the following elements:

- **Skin care:** To avoid injury and infection, good hygiene and proper moisturization is very important.
- **Massage:** Two basic types of massage are used to treat lymphedema.
- **Manual lymph draining** is a precise and gentle form of massage that helps mobilize the fluid and direct it to other pathways.
- **Soft tissue mobilization** is a type of massage used to release scar tissue and other tightness that might be contributing to the swelling. Sometimes massage is taught to patients or family members to carry out at home.
- **Exercise:** You may be instructed in stretching exercises to loosen up the tissues in the region or specialized exercises to help move the fluid out. You will be given written instructions for these exercises.
- **Bandaging:** This is a precise technique which uses cotton low-stretch bandages to apply constant pressure on the limb. Bandaging is usually done in combination with other methods.
- **Compression Garments:** These are elastic fabric garments similar to a girdle or support stocking that apply pressure to the arm or leg to help move fluid out and keep new fluid from collecting.
- **Medicine:** Sometimes antibiotics or other medications are prescribed as part of your lymphedema treatment plan.

—MD Anderson Cancer Center



Emma Detlefsen raising funds to help find a cure

now has lost more than 35 pounds of liquid from her legs and walked in her first ever 5K this past summer.

Or how about Pearl Ann Hinds? A promising young dancer, born in Barbados, was struck with primary lymphedema in her left leg at the age of 20. Being diagnosed with lymphedema can be devastating to someone who is just embarking on the beginning of adult life and Pearl Ann was no exception. Like most, there was a denial stage for her, she just wanted it to go away. But clarity came when she realized if she didn't "face

reality, then the legs of future generations would be lost". She took LE&RN's Face of Lymphedema Challenge by creating/ choreographing and performing in an inspiring video.

Now we come to a brave 8 year old named Emma Detlefsen. Born with lymphedema, she clearly doesn't like having the disease, but her faith and determination to find a cure is truly an inspiration. This little girl has been helping to raise funds for research through lemonade stands, and even helping legislators in Albany, New York sponsor and pass a resolution, not only to



Kathy with Dr. Griffin P. Rodgers, Director of NIDDK (National Institute of Diabetes and Digestive and Kidney Diseases)

honor her advocacy, but at the same time, provide LE&RN with two grants totaling \$200,000 for the LE&RN Patient Registry and Tissue Bank, part of New York state's 2015 budget. Emma has become the Youth Ambassador with LE&RN and has led her team, Emma's Incredibles, through several "5K Walk to Fight Lymphedema & Lymphatic Diseases" across the Brooklyn Bridge. "If I can do something hard for me, like walk across the Brooklyn Bridge and back, then maybe a smart scientist can do what's hard for them and find a cure."

Hearing words like these from a young girl are what continues to give Kathy Bates passion in her quest to find help for herself and the tens of thousands of others who suffer, but will not be silenced.

She has heard countless stories from people who hide in their homes because the disease can be so disfiguring and difficult to complete simple everyday tasks. They tell of being treated with such disrespect

from their doctors. They've been told it's all in their heads, there is nothing wrong with them, just go home and lose some weight, or you should appreciate your health and that you have arms and legs..get out of my office. Only to find out they really do have a disease...it really does exist.

To that Kathy has strong words, "I wish I could be like my character in (American Horror Story) Coven...be a witch and wave my wand over those doctors that have shunned their patients and told them just to lose weight. I want those guys to know, for just 24 hours, what it's like to live with lymphedema."

During Kathy's process of bringing a face to lymphedema, she has learned so much more than she expected. "The lymphatic system has been somewhat of a mystery to the medical community since the beginning of time, and it continues to be." However she found optimism in a meeting with the National Institutes of Health (NIH) she attended. The takeaway message she got from them — once we unlock the mysteries of the lymphatic system, we could discover cures for heart disease, obesity, kidney disease...you name it.

Educating the medical community seems to be the key. It's disheartening to hear that doctors spend very little time learning about the lymphatic system, it's not even on their state licensing exams. Ms. Bates has learned so much through conversations with doctors, including Dr. Stanley Rockson, LE&RN's founding chair of the scientific and medical advisory council. "In all fairness to the doctors," she says, "we need to remember in the old days there were only a few medical journals that could be read to keep up on the advancements in medicine. Today they are just inundated." Which begs the question how to share the information? How can we get the information out to medical community so



Kathy meets with Senator Charles Schumer, D-NY

they can treat their patients, or at the very least be able to diagnose and refer these patients for proper care.

Getting the word out any way she can is Kathy Bates main objective. "You say the word AIDS or Breast Cancer and everyone immediately knows what it is. But when I say lymphedema and start to tell them about it, their eyes glass over. It's like trying to market a movie that you know will NEVER be seen."

Despite the lack of information and doctors treating the disease...she is encouraged by research and studies that



Kathy with Dr. James Madara, Executive Vice President and CEO of the AMA



are surrounding lymphedema around the world. Kathy has been working with Senator Charles Schumer of New York and the NIH to get the funding necessary to continue the much needed research.

In addition to seeking avenues for funding, Kathy has met with Dr. James Madara, Executive Vice President and CEO of the American Medical Association, hoping to bring to light

the critical need to arm the medical community with the proper education to fight this commonly overlooked disease.

While the battle continues on, Kathy remains undeterred in her crusade. The Oscar-winning actress recently was honored with a star on the Hollywood Walk of Fame, which she dedicated to Emma. It seems her story has come full circle as she recalls a photo taken long ago as an eight year old child together with her Aunt Lee in front of the former Grauman's Chinese Theater. Aunt Lee died from breast cancer. "She didn't have the care that I've had, she didn't have the years that I've had," Kathy said. "These have been the best years of my life and it just breaks my heart. Now I understand what my mother and aunt were going though and I didn't at that time. So I just want to be real and I just want to give back."

We can all do our part to help further the cause...visit lymphaticnetwork.org to find out what you can do to join Kathy Bates and all the brave men and women, boys and girls fight lymphedema and lymphatic disease and someday find a cure.

—Bonnie Jean Thomas, Editor, *A Wellness Update*

SQUEAKY WHEEL FUNDING

When it comes to government grants and funding, it is painfully apparent that the "Squeaky Wheel" gets the lion's share of the budget. In the United States, there are a reported 1.2 million AIDS cases, while there are 10 million people affected by Lymphedema. Yet, President Obama's budget request for 2017 includes \$27.5 billion for AIDS research and nothing in the budget for Lymphedema research.

An estimated one million people are affected by Parkinson's in the United States and in 2016, the NIH (National Institute of Health) budgeted \$152 million for Parkinson's research. The one bright spot for Lymphedema funding comes from Senator Charles Schumer (D-NY) who requested \$70 million for Lymphedema and Lymphatic research. However, the request, is still awaiting approval.



Kathy Bates, LE&RN Spokesperson

LE&RN

Education. Research. Advocacy.

Up to 10 million Americans suffer from **lymphedema**—a life-altering and debilitating disease. This includes wounded veterans, children who inherit it, and ovarian, prostate and melanoma cancer survivors. In addition, up to 30% of breast cancer survivors will develop lymphedema.

Become a Supporting Member today for as little as \$5 a month at

www.LymphaticNetwork.org

Join us and Kathy Bates in finding a cure.



Lymphatic Education
& Research Network

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