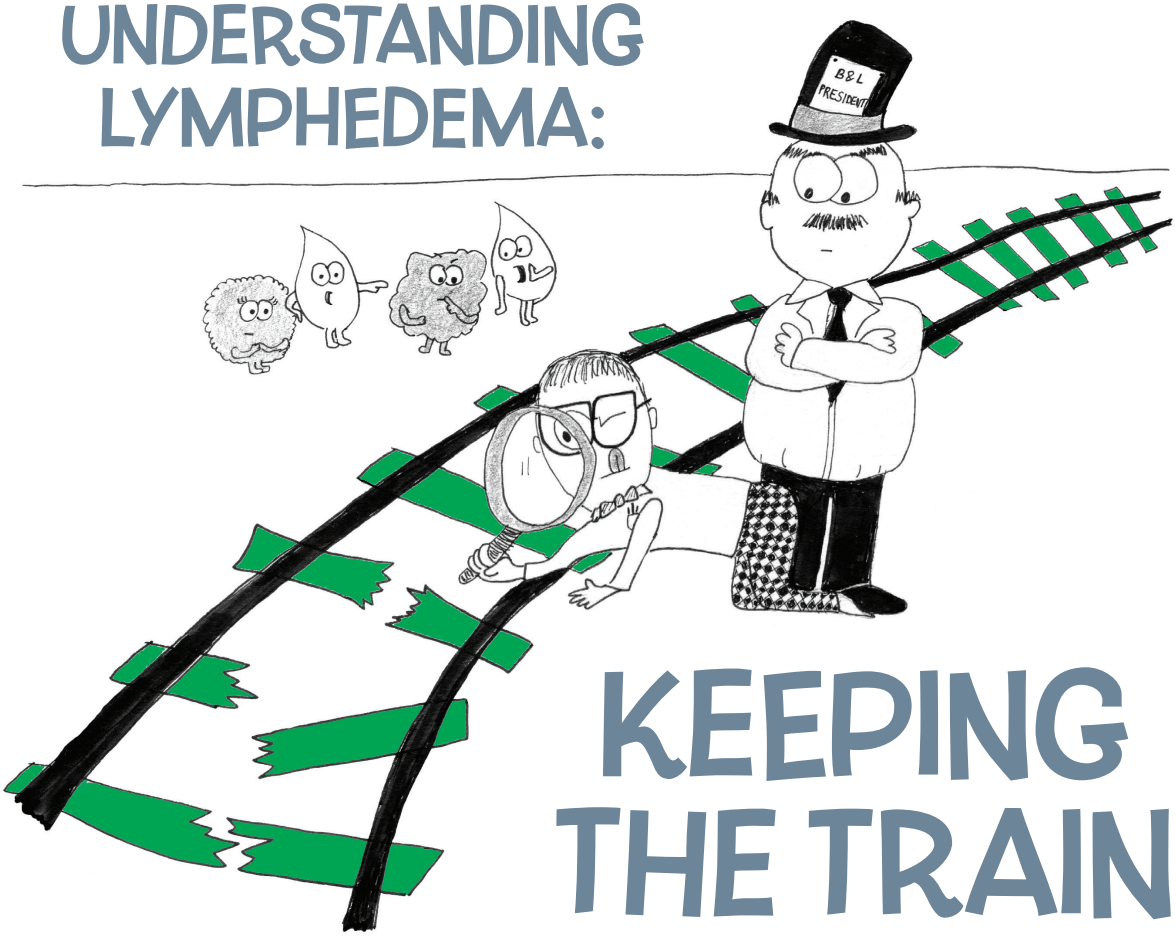
Lymphatic Education
& Research Network

UNDERSTANDING LYMPHEDEMA:



KEEPING THE TRAIN ON TRACK

By Dhruv Singhal, MD
Illustrated by Megan Belanger, LMT, CLT
Foreword by Kathy Bates

Art Direction/Design: Michael D. Minichiello/MDM Graphic Design, Inc.

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UNDERSTANDING LYMPHEDEMA: KEEPING THE TRAIN ON TRACK

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FOREWORD

During my time serving as the National Spokesperson for the **Lymphatic Education & Research Network**, I have had countless opportunities to engage with physicians and patients. Their first question is always, "What exactly is the lymphatic system and how does it work?" I have struggled to find a clear and concise way to explain the essential function that lymphatics play in the body's vascular and immune systems. It is essential to emphasize the severity of lymphatic disease (LD) and lymphedema (LE) when that system is damaged. Otherwise this incurable disease goes undiagnosed for years while it progresses to stages more difficult, if not impossible, to treat.

In this entertaining and clever book by Dr. Dhruv Singhal of Harvard Medical School, with charming cartoons by Certified Lymphedema Therapist Megan Belanger, the mystery of how the lymphatic system works is revealed in simple terms. This book will serve to educate children and adults suffering with lymphedema as well as a model for physicians to better understand the disease process. I learned facts I didn't know, so I will keep this book handy for my future engagements. I sincerely hope *Keeping the Train on Track* will find its way to clinics and hospitals everywhere.

My gratitude always to Bill Repicci, our CEO of LE&RN, for his support of this project and for his indefatigable toughness both here in the US and around the globe educating and advocating for those of us who suffer with lymphedema. I am one of them.

Finally, I've often quoted Isaiah 11:6, "And a little child will lead them." So, I want to bless Kalyan Singhal for inspiring his dad and all of us as we march slowly but surely to a cure.

Kathy Bates
January 2020
Los Angeles, CA

INTRODUCTION

There is a well quoted statistic that only 15 minutes are spent in all 4 years of medical school dedicated to the lymphatic system. Looking back, that sounds about right.

In 2012, after returning to the States from Taiwan where I completed my fellowship training, I was committed to starting a lymphatic program. However, doing so, I had to not only go and explain lymphatic surgery procedures to patients and physicians, I had to explain "What is lymphedema?". In giving countless lectures to patient survivor groups, medical societies, and cancer centers, I was often faced with blank stares while trying to explain an entire disease process and potential surgical interventions in 45 minutes.

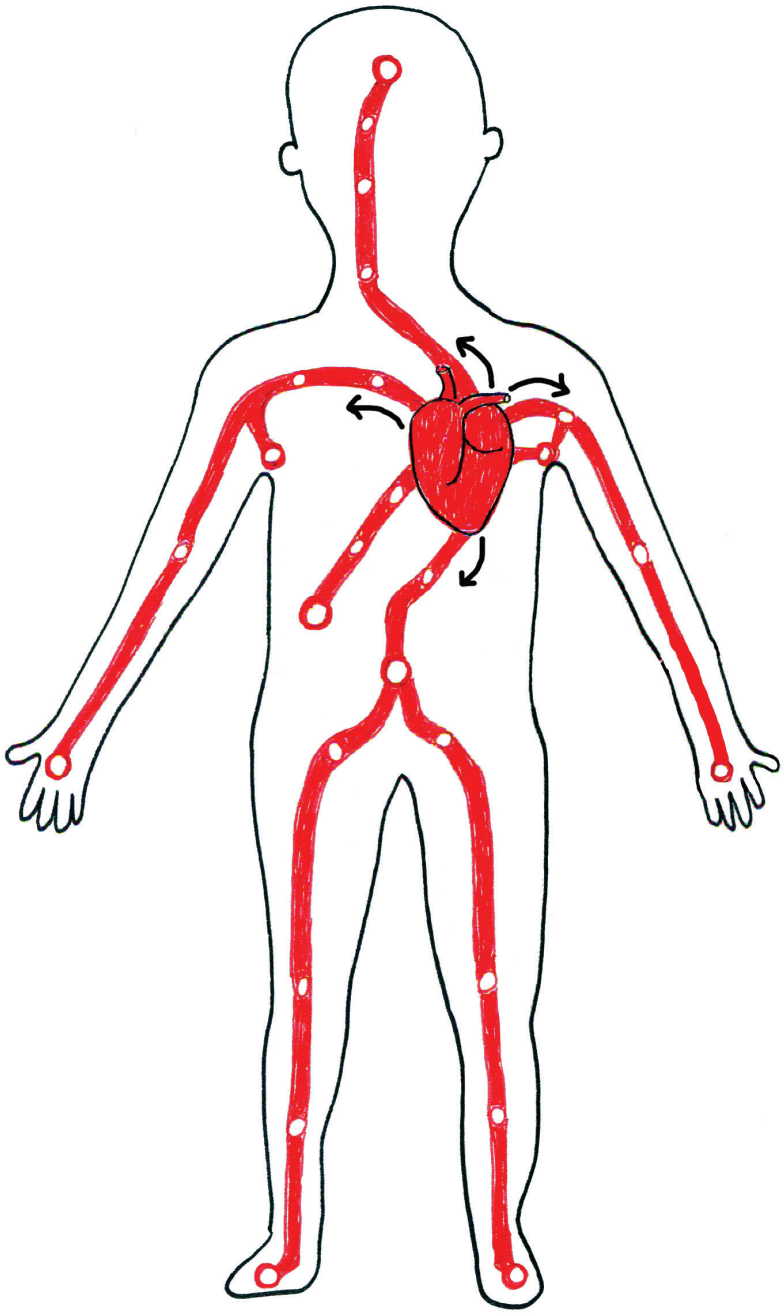
In the midst of this experience, my son, Kalyan, was born. Kalyan loved trains. Sitting on our living room floor one day Kalyan was moving his toy trains this way and that and the analogy hit me. After months of playing the analogy out in my head, I began trialing it in lectures. Soon, instead of blank stares, I was getting the knowing nods that gives a speaker assurance that their message is getting across. I began using the analogy with patients in clinic and hearing, "This is the first time I really understand lymphedema."

I was a lymphatic surgeon for 5 years when my fortune had my paths cross with Bill Repicci, the President and CEO of LE&RN. Bill is a tireless leader and advocate for all patients with lymphatic disorders. In our first meeting, it became clear that we shared similar visions. In the midst of an evolving partnership and incredible friendship, he invited me to speak at the first CME course for physicians in 2018 at the Harvard Club in Boston on "The Overview of Surgical Treatments for Lymphedema". By this time, the train analogy had become a fixture in my talks. As the course ended, an exuberant young woman approached me. She was interested in converting the train analogy into cartoon panels for her website.

Megan Belanger is a certified lymphedema therapist AND an accomplished cartoon artist. Incredible. She had the talent to bring the train analogy to life and understood lymphedema. Megan tactfully merged her intimate knowledge of lymphatic disorders, an incredible sense of humor, and artistic talent into the beautiful panels you are about to read. The development of this book was the natural next step.

Megan and I hope that regardless of whether you are a patient with lymphedema, a health care provider learning about lymphedema, or a lymphedema expert, that you will find this analogy helpful. After all, we must first understand.

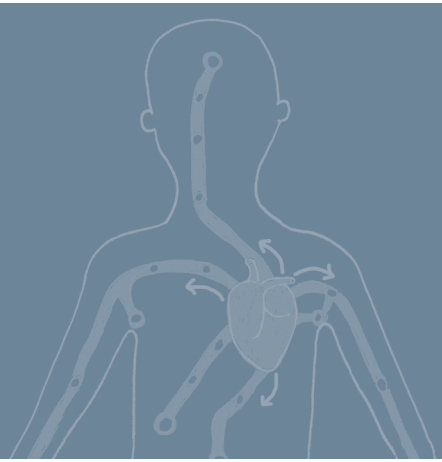
Dhruv Singhal, MD
January 2020
Boston, MA



SECTION 1: WHAT IS LYMPHEDEMA (LE)?

Imagine your heart is a central train station. From that train station, train tracks go to every part of your body.

*The red train tracks represent **arteries**.*

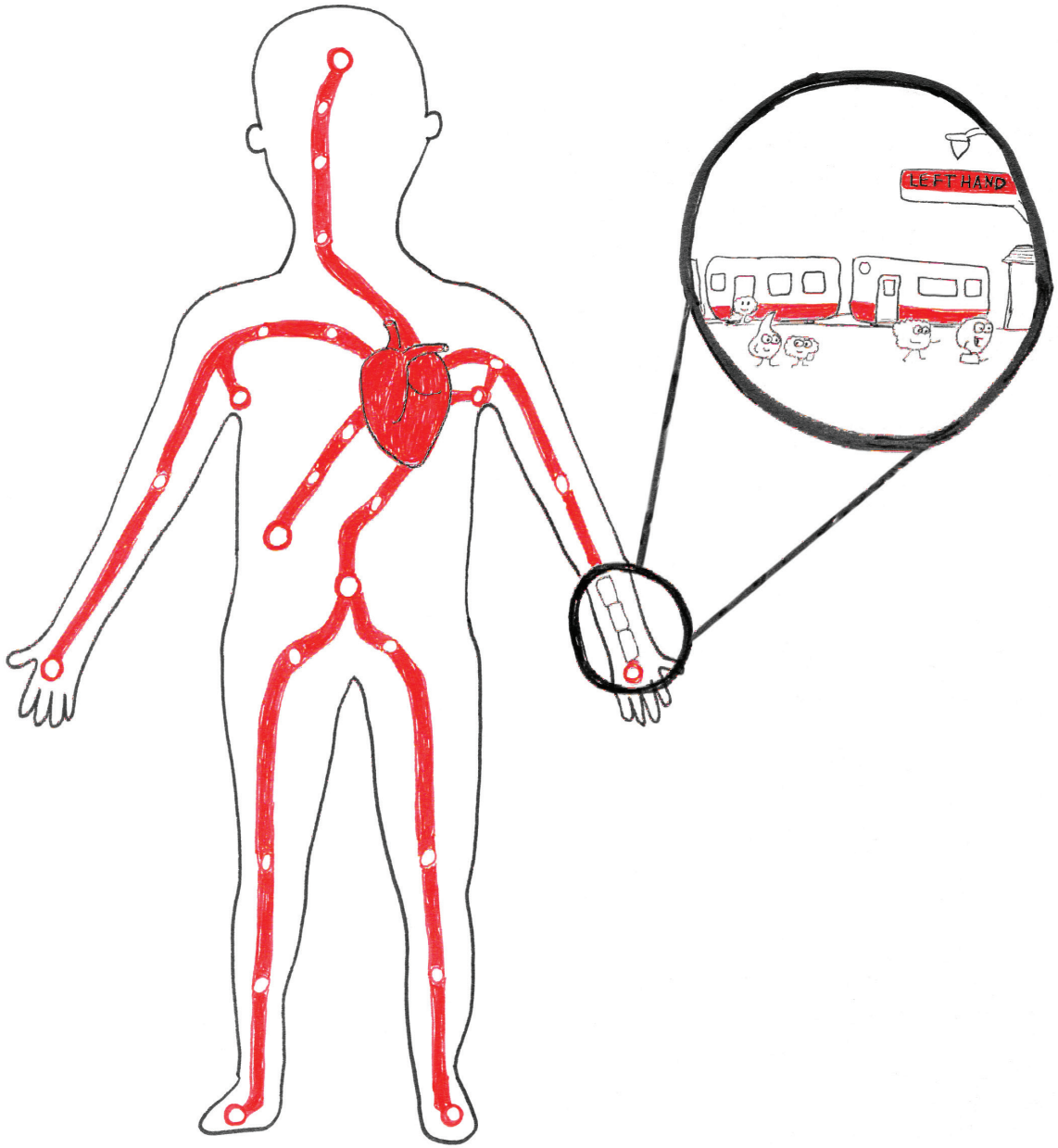



ALL ABOARD!
LEFT ARM & HAND
OUTBOUND
8:59

Every morning, red trains prepare to leave the central station on the red train tracks. *There is a different red train dedicated to each part of the body.* When the red train leaves the station, the train is full and every passenger has a seat.

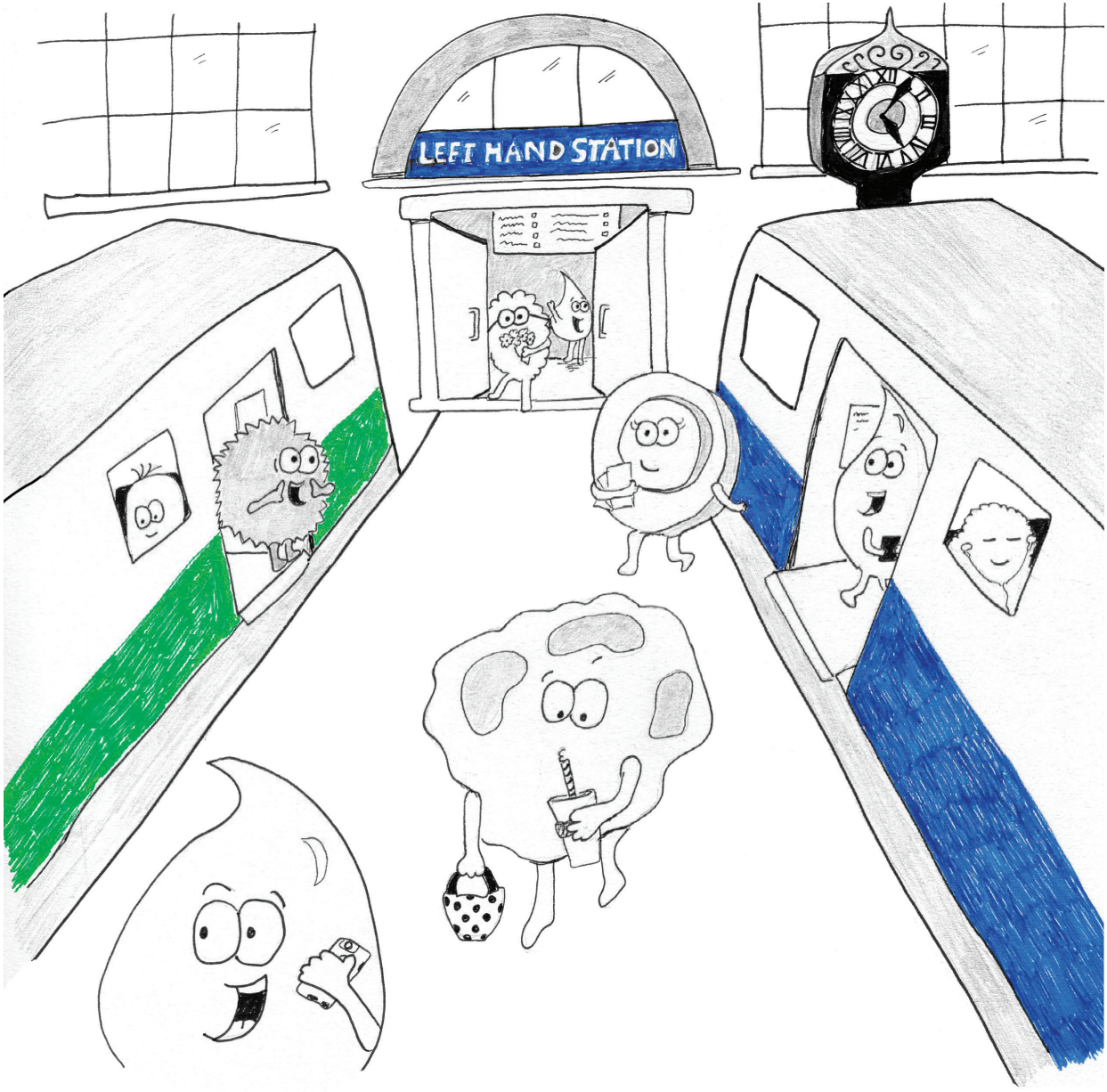
In this example, let's focus on the red train going to the left arm and hand. It is approaching 9:00 AM, and the red train is loading passengers. The train leaves the station at 9:00.

Blood (cells and proteins) *are pumped away from the heart and into arteries that go to the rest of the body.*


LEFT HAND

The train dedicated to the left arm and hand has to make stops at many substations as it travels to the end of your fingertips. Its first drop-off sub-station is at the left armpit, after which it continues its journey down the arm, stopping often to drop off passengers so they can go to work.
By the time the train hits the end of the line, or the tips of the fingers, all the passengers have gotten off the train.

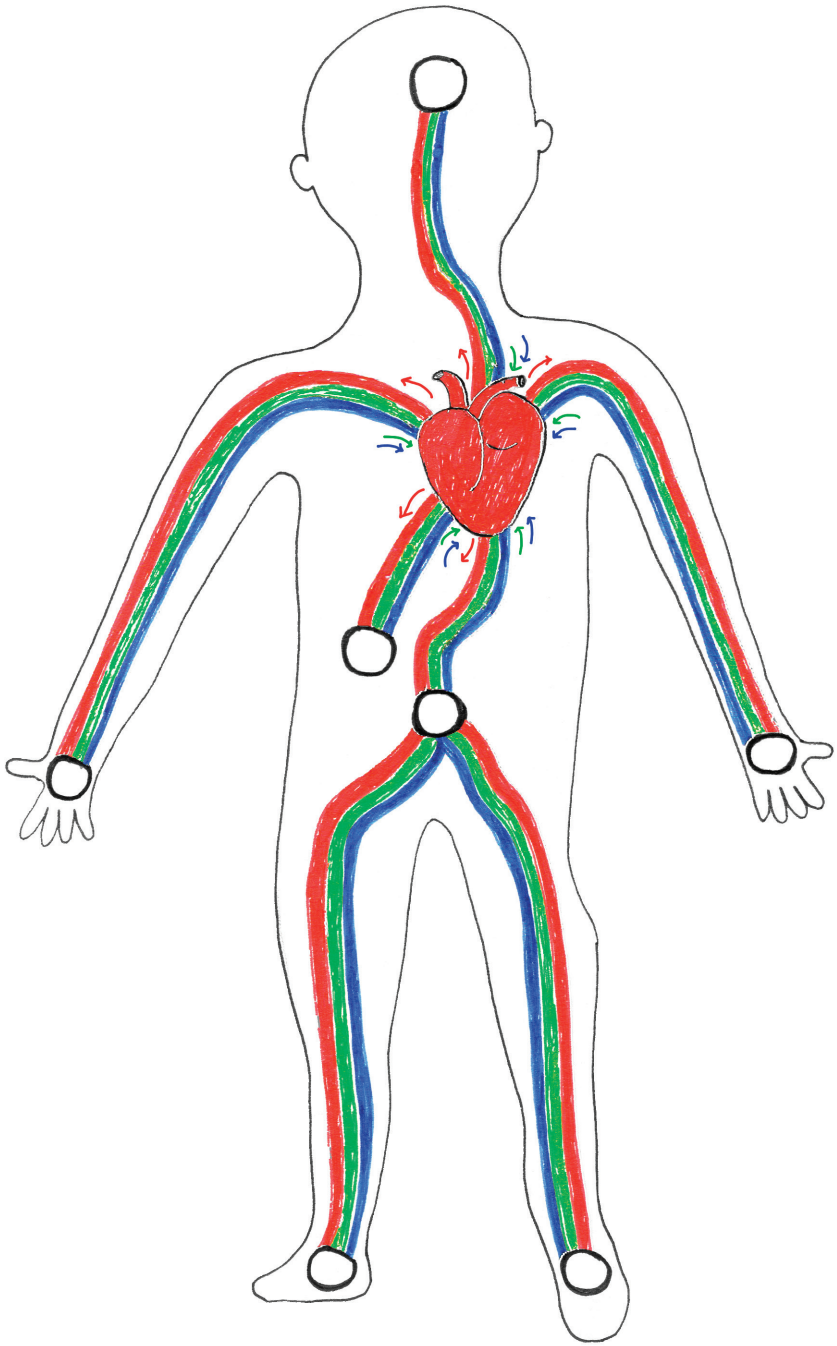
*The **arterial system** is releasing cells and proteins constantly as it travels down the arm.*


LEFT HAND STATION

It is now 5:00 PM, the end of the workday. All the morning passengers from the red train want to get home! There are two sets of trains that will bring all those passengers back home (to the heart). There is a *blue* train and a *green* train.

*The blue trains represent **veins**.*

*The green trains represent **lymphatics**.*

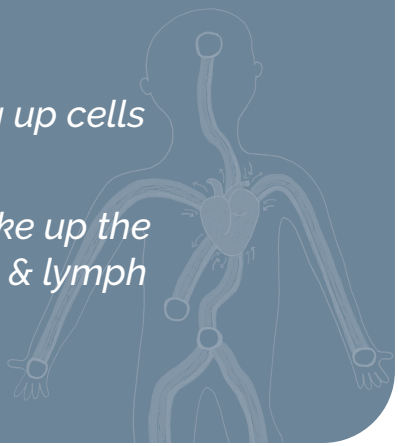


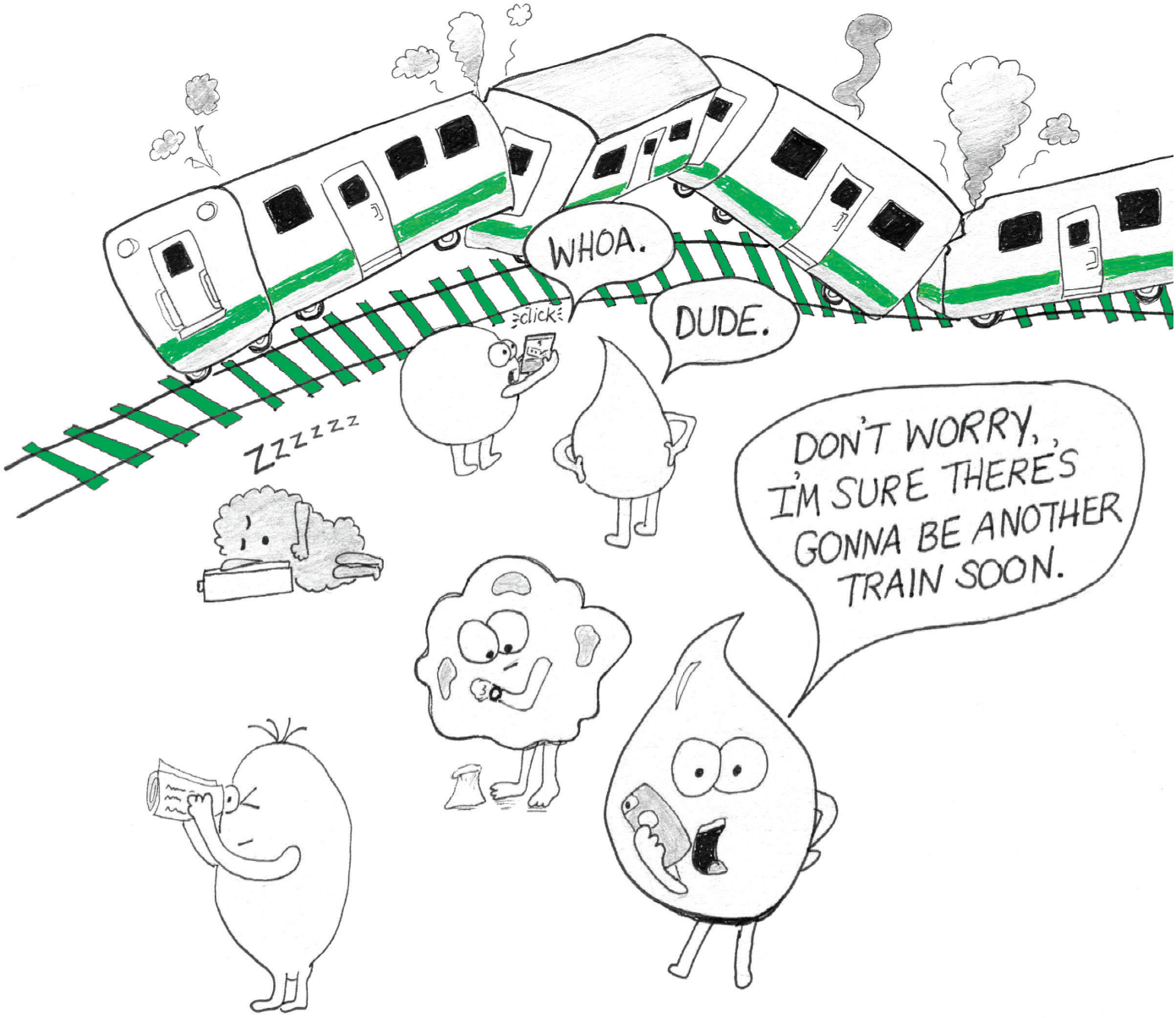
If everything is working well, the blue and green trains are on time and there are enough seats for all those morning passengers to return home.

All the tracks (red, blue, and green) are managed by the B&L Line.

The veins and lymphatics are constantly picking up cells and proteins and returning them to the heart.

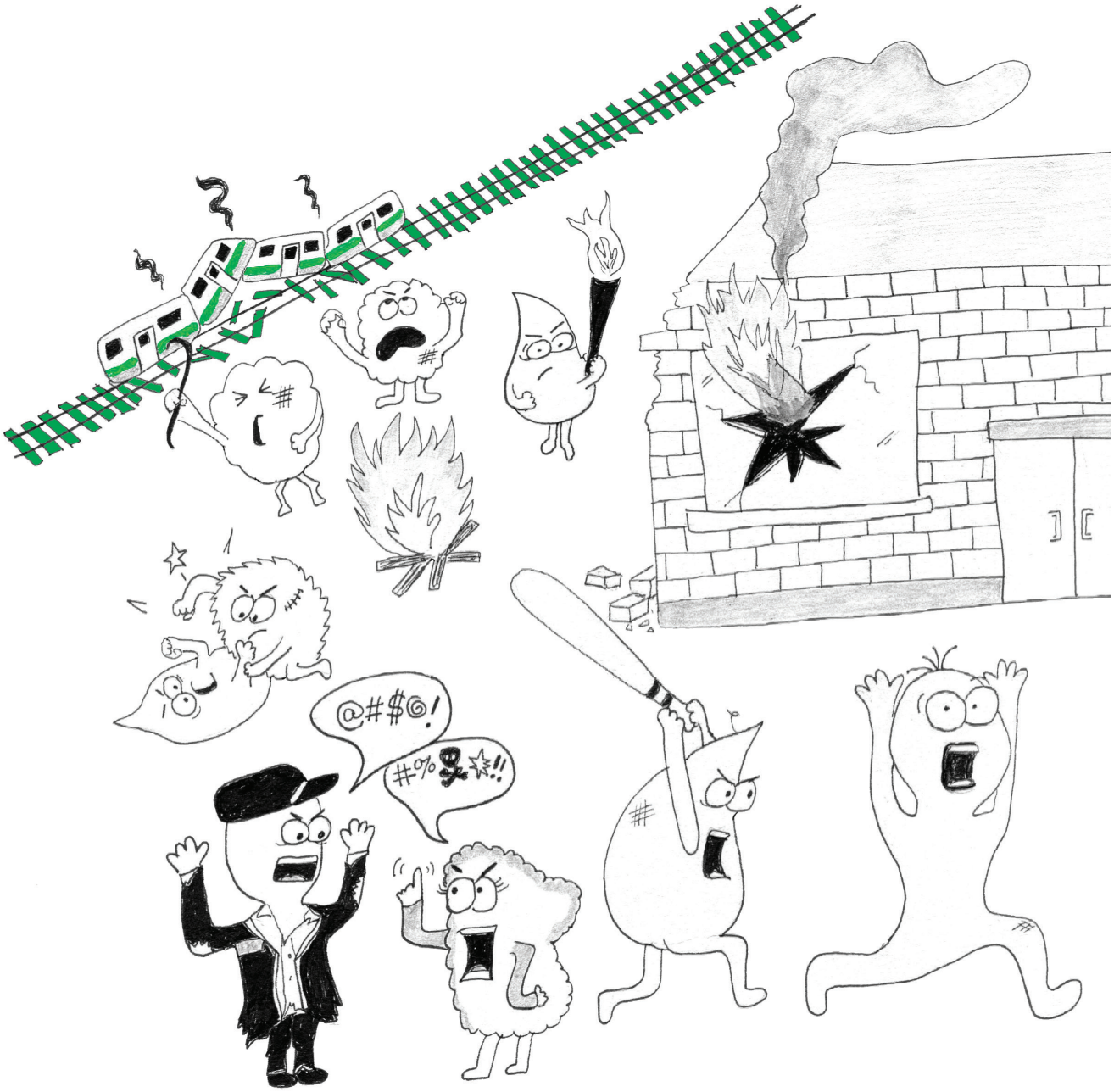
*Together, the arteries, veins, and lymphatics make up the body's **vascular system** which transports blood & lymph (B&L) to and from the heart.*




WHOA.
DUDE.
click
ZZZZZZ
DON'T WORRY, I'M SURE THERE'S GONNA BE ANOTHER TRAIN SOON.

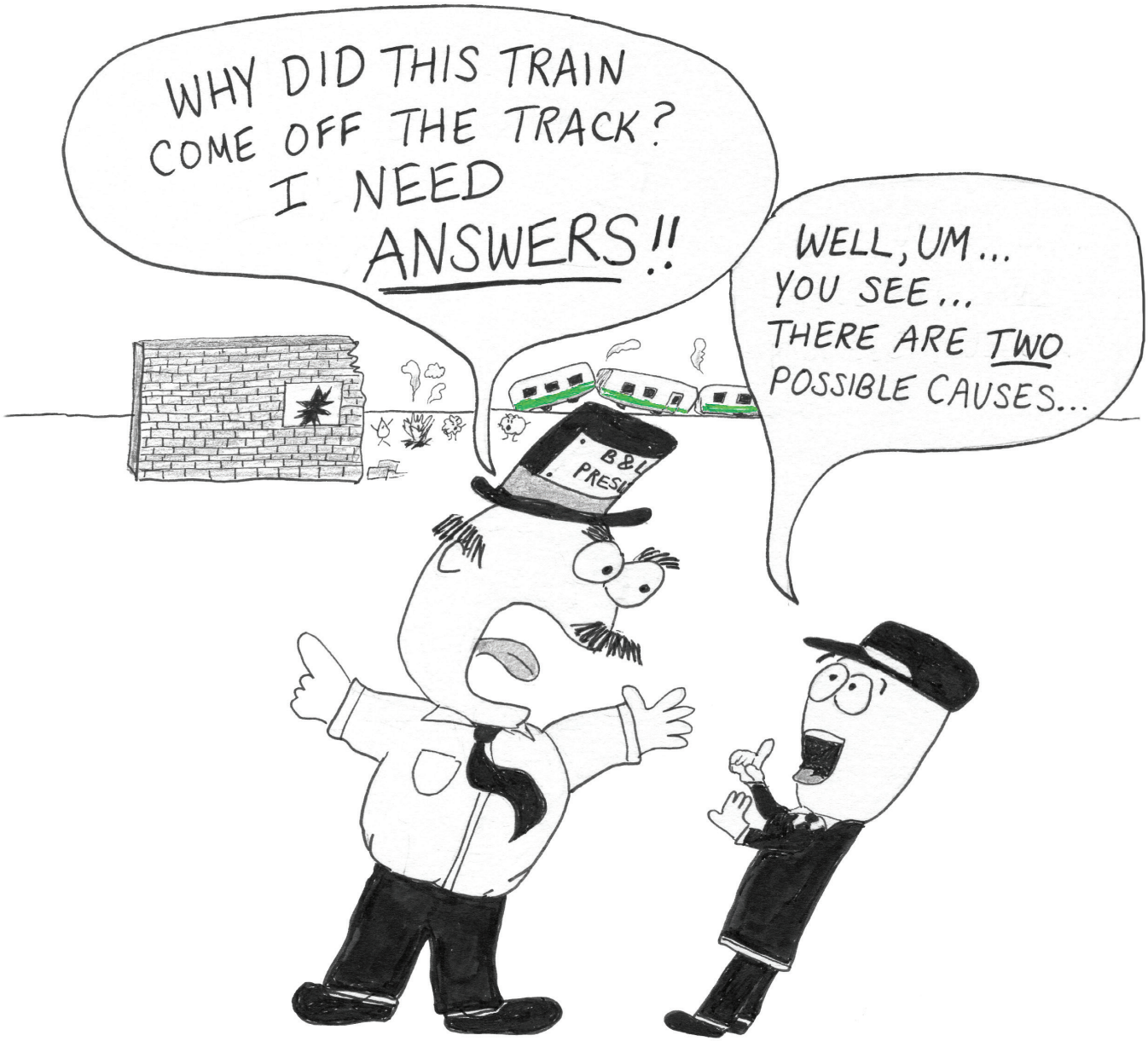
But what if one day something goes wrong, and the green train breaks down? Suddenly, some of those passengers from the morning are unable to get home, and they get stranded. At first, the stranded passengers are calm as they wait for the next train to come and take them home.

*Initially, when the lymphatics are damaged, there is a backup of cells and proteins or **lymph**. At first, this backup may not cause any symptoms but may be detected using sophisticated devices.*



But what if someone told them, “There *is* no other train coming”? Now the passengers are stranded for a long time, unable to get home, and just...*stuck*. They might get a little ticked off. And then they might start getting angry. And they even might start to riot.

*Eventually, the body may respond to the abnormal build-up of lymph with **inflammation**. It is this inflammation that ultimately leads to the common symptoms of lymphedema, including heaviness and tightness to name a few. Unfortunately, the inflammatory process will get worse unless the patient finds a way to get rid of the excess lymph.*


WHY DID THIS TRAIN COME OFF THE TRACK? I NEED ANSWERS!!
WELL, UM... YOU SEE... THERE ARE TWO POSSIBLE CAUSES...

SECTION 2: WHAT CAUSES LYMPHEDEMA?

The president of the B&L Line is very upset and demands answers from the train's conductor. Why did the green train come off the track?! The conductor explains that there are two possible causes.

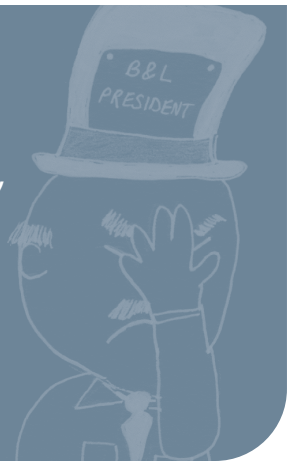
*There are **two** causes of lymphedema...*

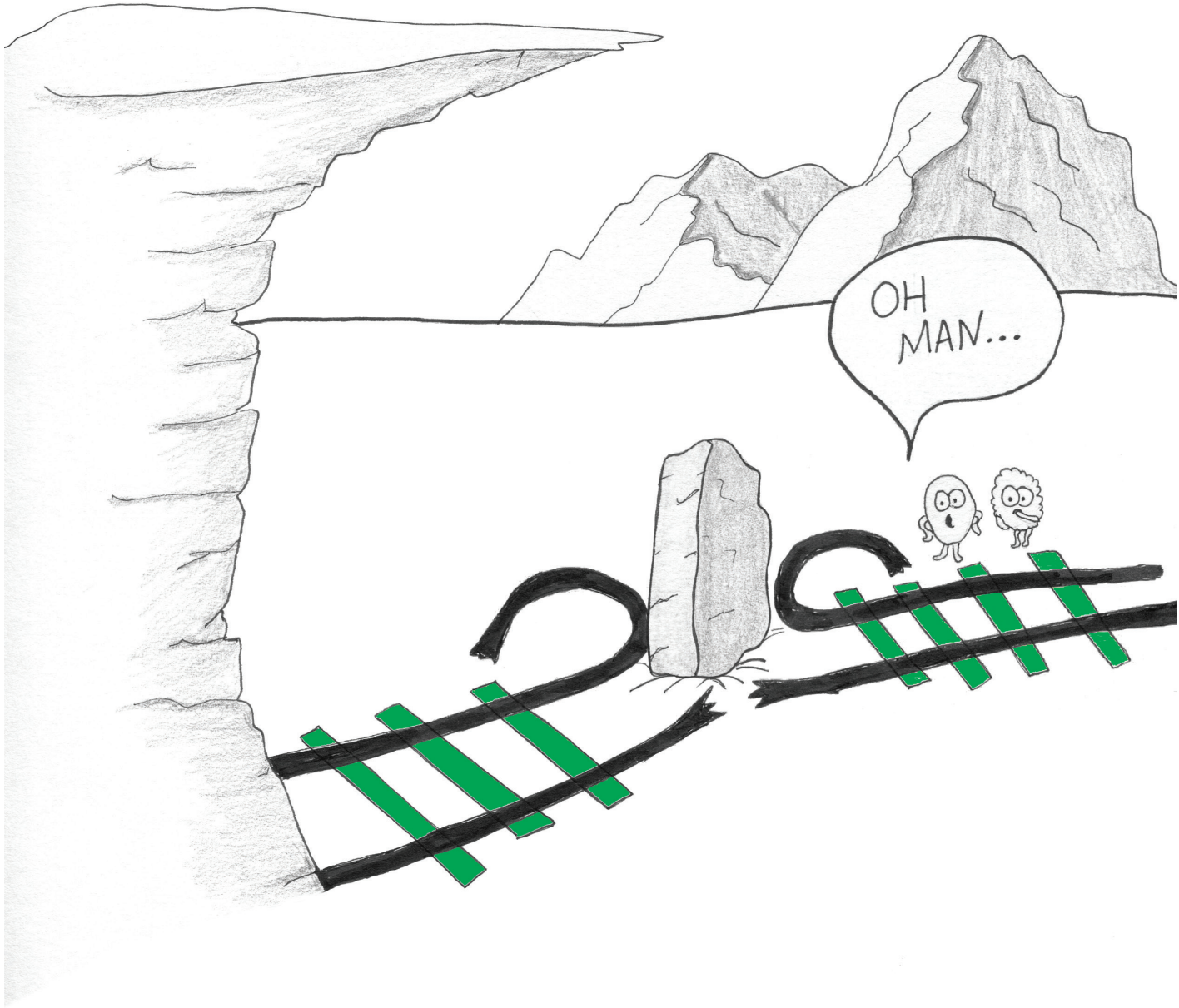

ALLLLLL DONE, SIR!
B&L PRESIDENT

Primary Lymphedema

One reason is that the track was never built properly in the first place.

*The first cause, termed **Primary Lymphedema**, means that the lymphatic system was never fully developed at birth. In this case, the symptoms can develop at any point in life, but the most common times are at birth, in the teen years, or when a person is in their 30s. Hormonal changes in the body likely play a role in the disease developing later in life.*

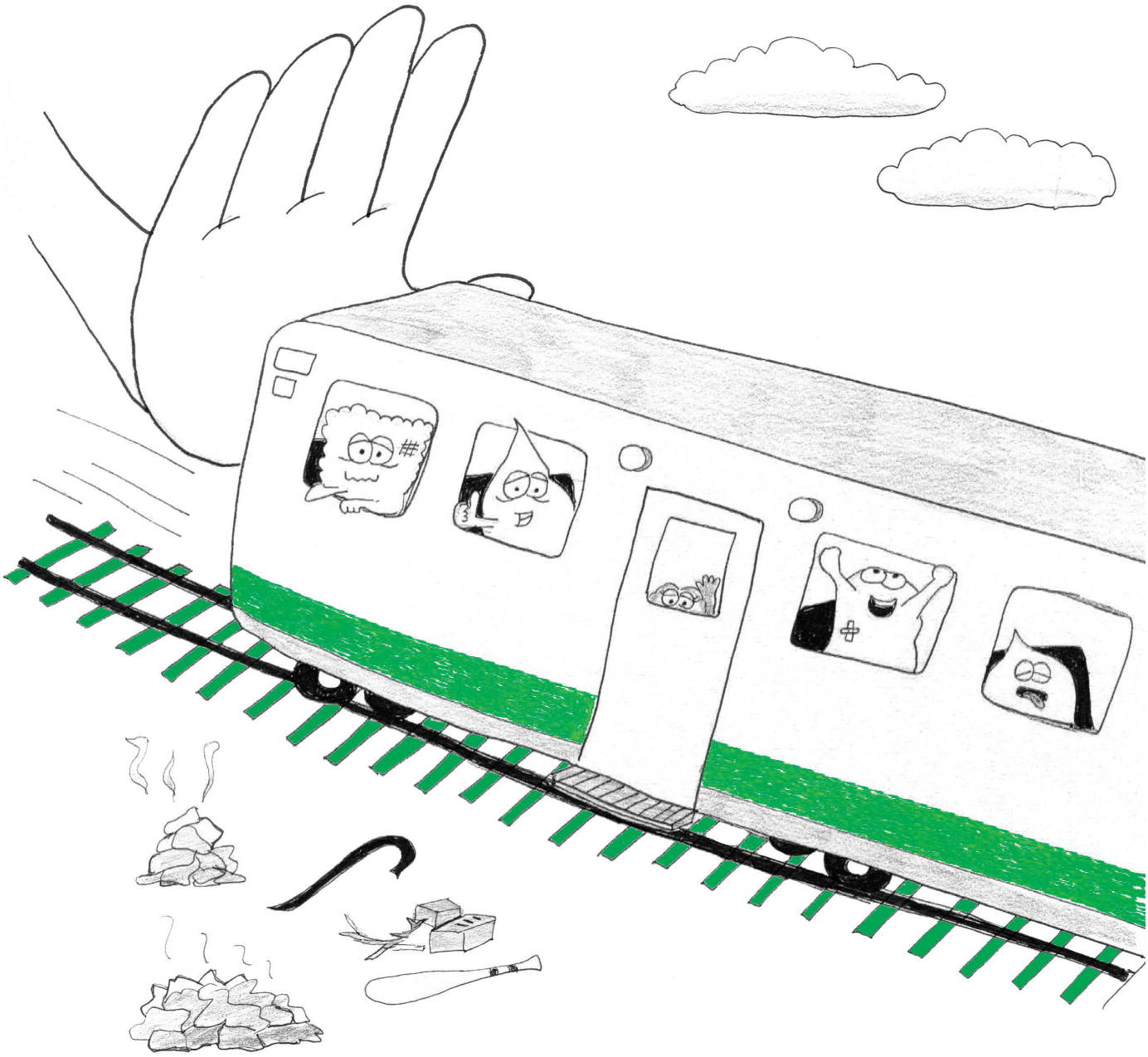



OH
MAN...

Secondary Lymphedema

The second possibility is that the track was perfectly built originally, but then it got damaged.

*The second cause, termed **Secondary Lymphedema**, means that the perfectly healthy lymphatic system was damaged. Worldwide, the most common cause of lymphedema is a parasite infection called filariasis. In the United States, the most common cause of lymphedema is the removal of lymph nodes to prevent the spread of cancer.*

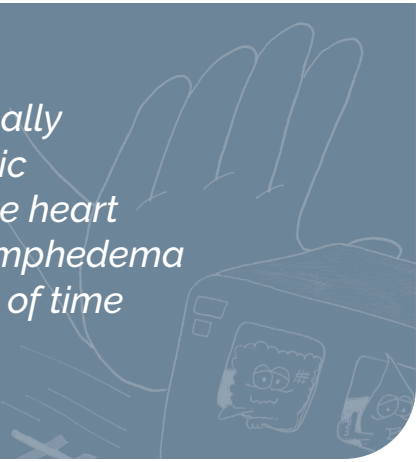


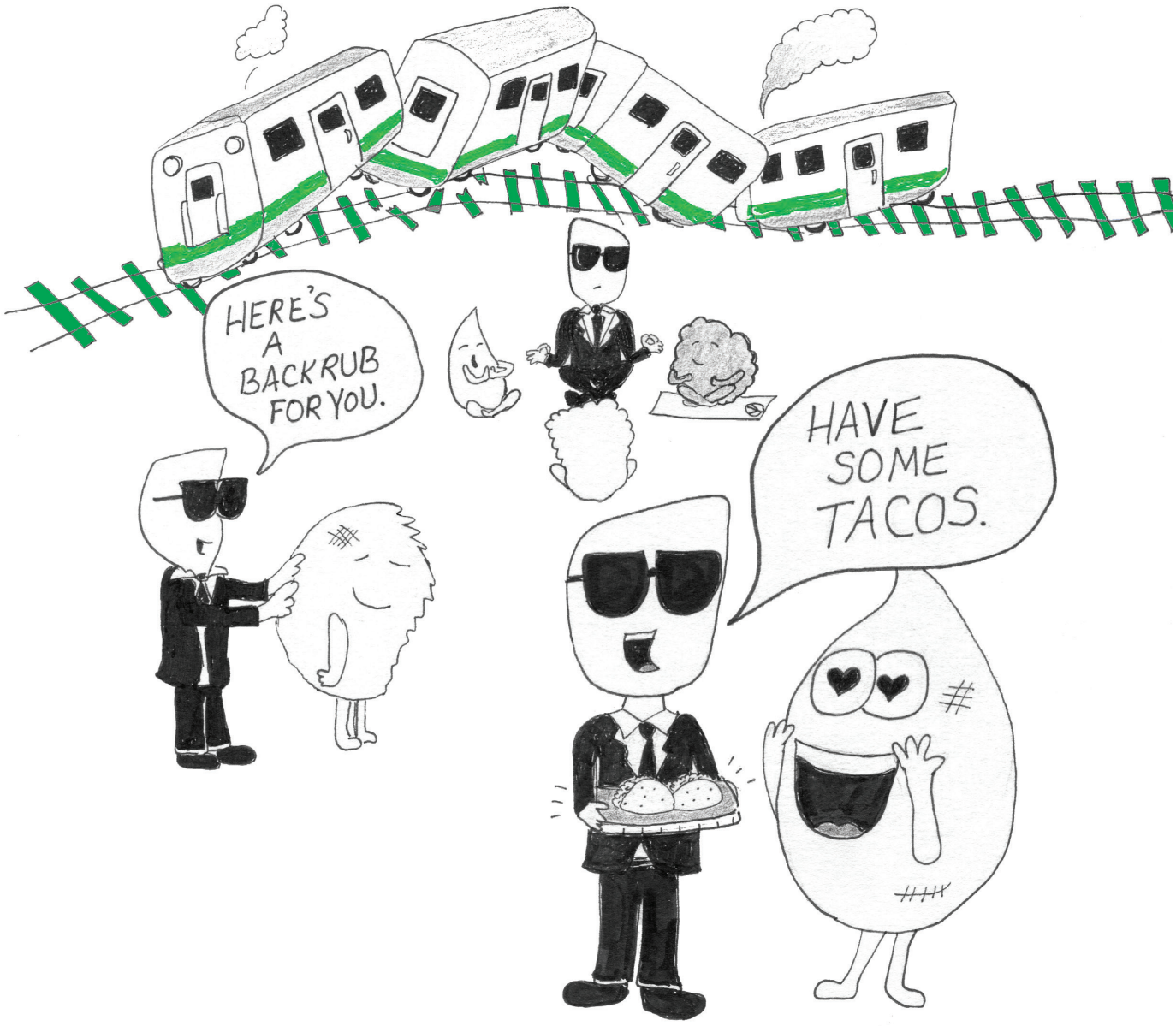
SECTION 3: HOW DO WE TREAT LYMPHEDEMA?

Physical Therapy

Now, having rioting passengers is not making the train company look good. They decide they have to get the passengers home, but they can't get the green train to work. One way to get all the passengers home is to put them back on the train. The broken green train is then pushed home.

Lymphedema therapists *are essentially manually guiding the cells and proteins into the lymphatic channels. They then push the lymph back to the heart (central train station). This is the standard in lymphedema treatment, and as you can imagine, takes a lot of time and energy and is usually life-long.*

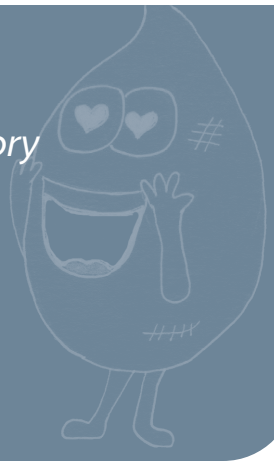


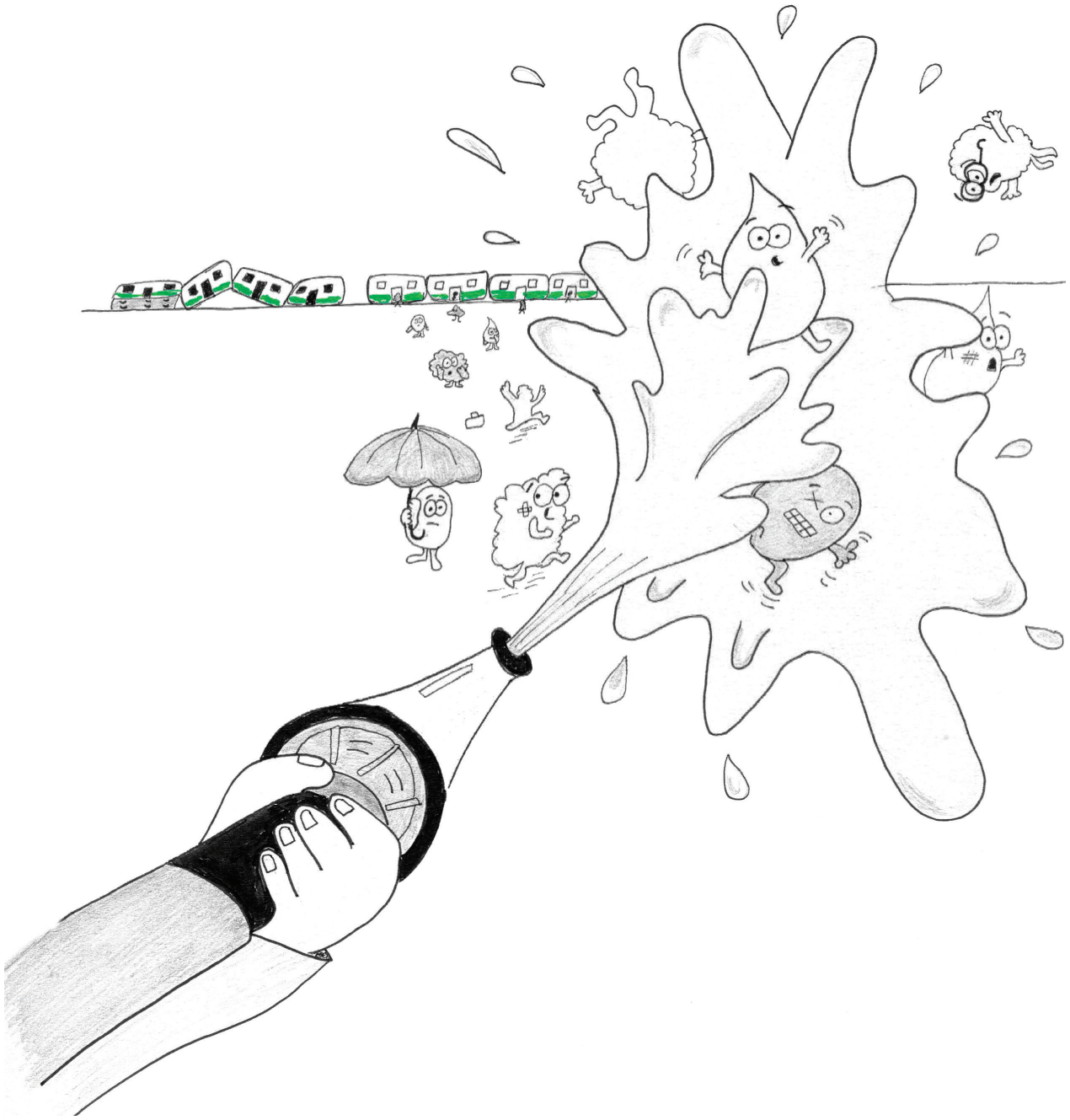

HERE'S A BACK RUB FOR YOU.
HAVE SOME TACOS.

Medicine

The B&L Line president is really worried because the rioting passengers are making him look bad. So, he decides to send in workers to calm them down.

*There is no medicine currently on the market to treat lymphedema. However, we know that anti-inflammatory medications may help the disease. But because these medications can have **severe side effects**, studies are currently underway to determine which, if any, anti-inflammatory medicines may be beneficial for lymphedema patients.*

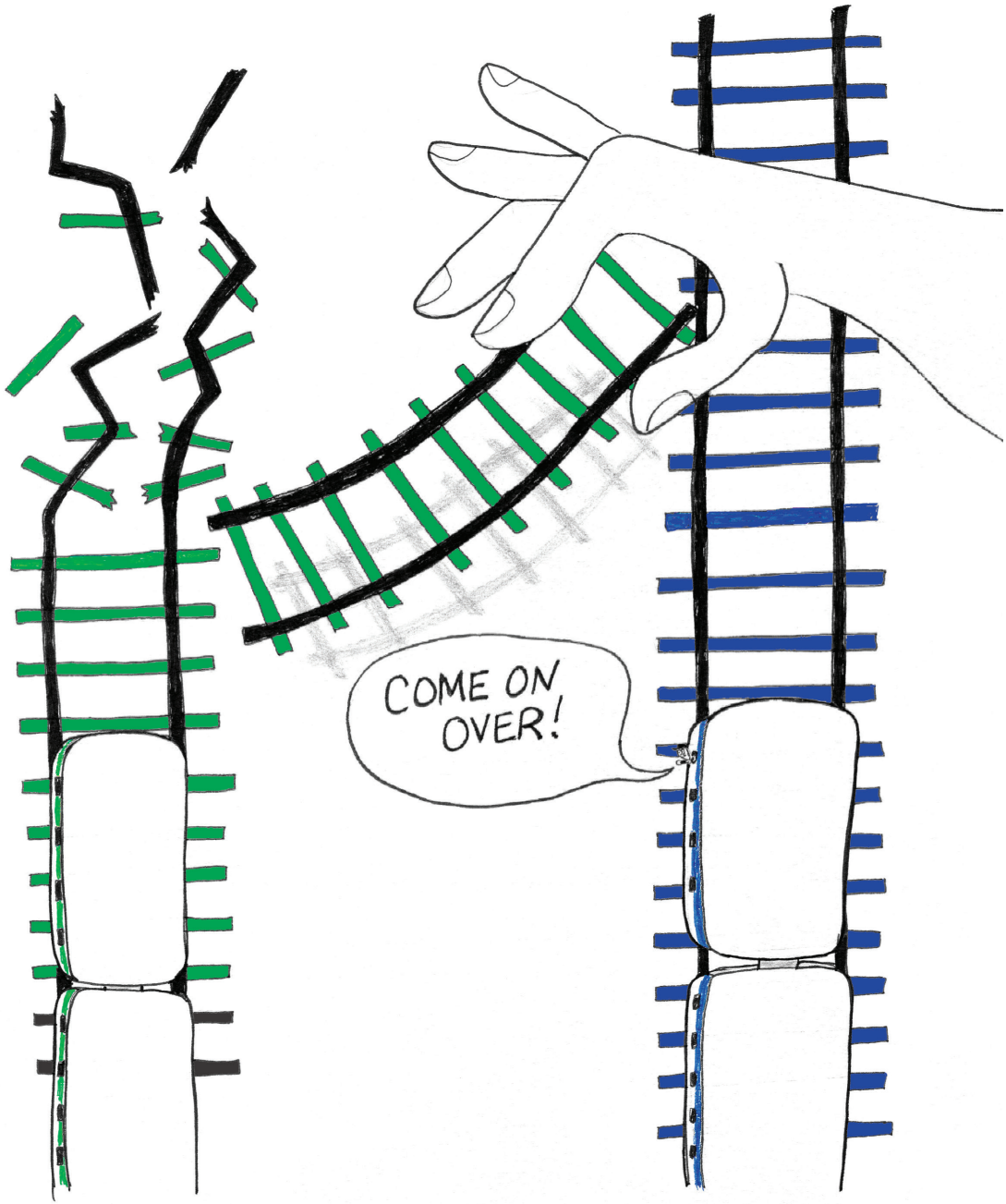




Surgery

Or the train company may decide to simply get rid of the rioting passengers. But remember, the green train is still broken! So, more stranded passengers are about to replace the ones they just got rid of!

In certain patients, the build-up of lymph leads to abnormal build-up of fat. Excisional procedures ***(e.g., liposuction)*** *remove fat that has built up. But the lymphatic system is still not working, so more lymph is going to build up again as well as fat. The only way to prevent more fat from developing is to remain in compression all the time following the liposuction procedure.*


COME ON OVER!

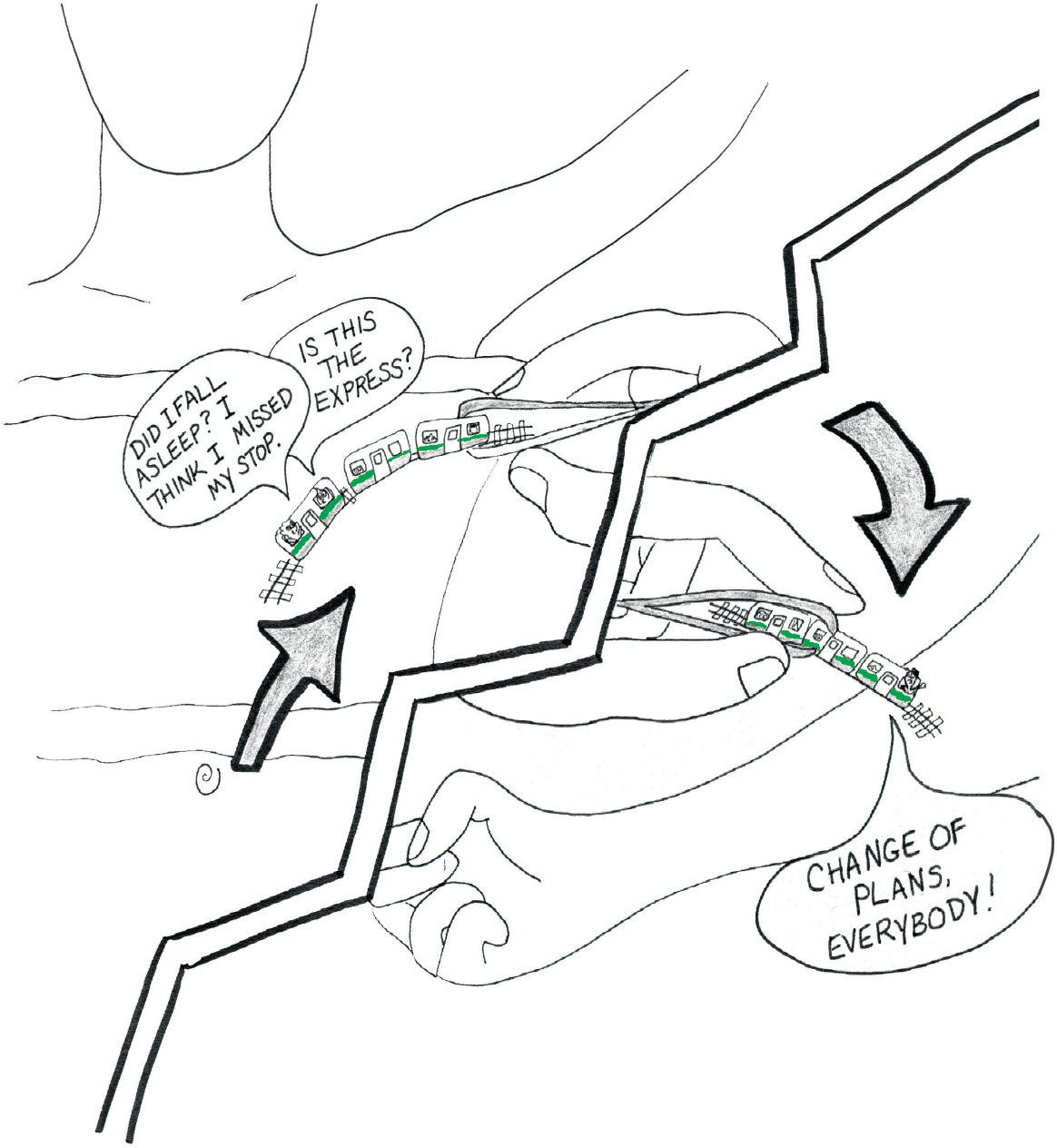
Let's say the train company decides they want to find the source of the problem and fix it. They realize any fix is likely not going to be a perfect solution. *At the very least, they want to get the train back on track.* Let's say they inspect the green train tracks and discover a big crack in them. What they might decide to do is build a quick connection between the green train tracks and the blue train tracks. Now, the green train can bypass the crack and get back home (to the heart) on the blue train track system.

***Physiology** means "the science of the normal function of living things." Physiologic surgical treatments for lymphedema means that we are going to try and improve how the lymphatic system is working through surgery. There are two main physiologic approaches. The one being described in this panel is termed a **lympho-venous (LV) bypass**. The surgeon makes an incision, finds lymphatics, and connects them to veins to create a new drainage pathway for lymph.*


YEAH, MAN, THERE'S NOTHING ELSE I CAN DO HERE.

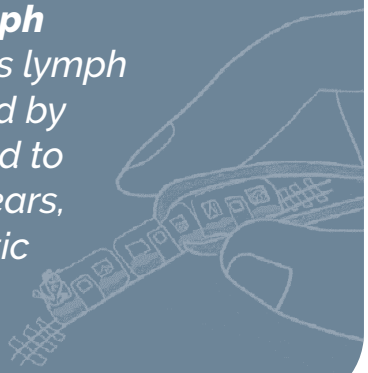
Or, what if the train company found that not only was there a big crack in the green tracks, but the green train was badly damaged. This means that even if they made the connection to the blue train track system, the green train wouldn't be able to move.

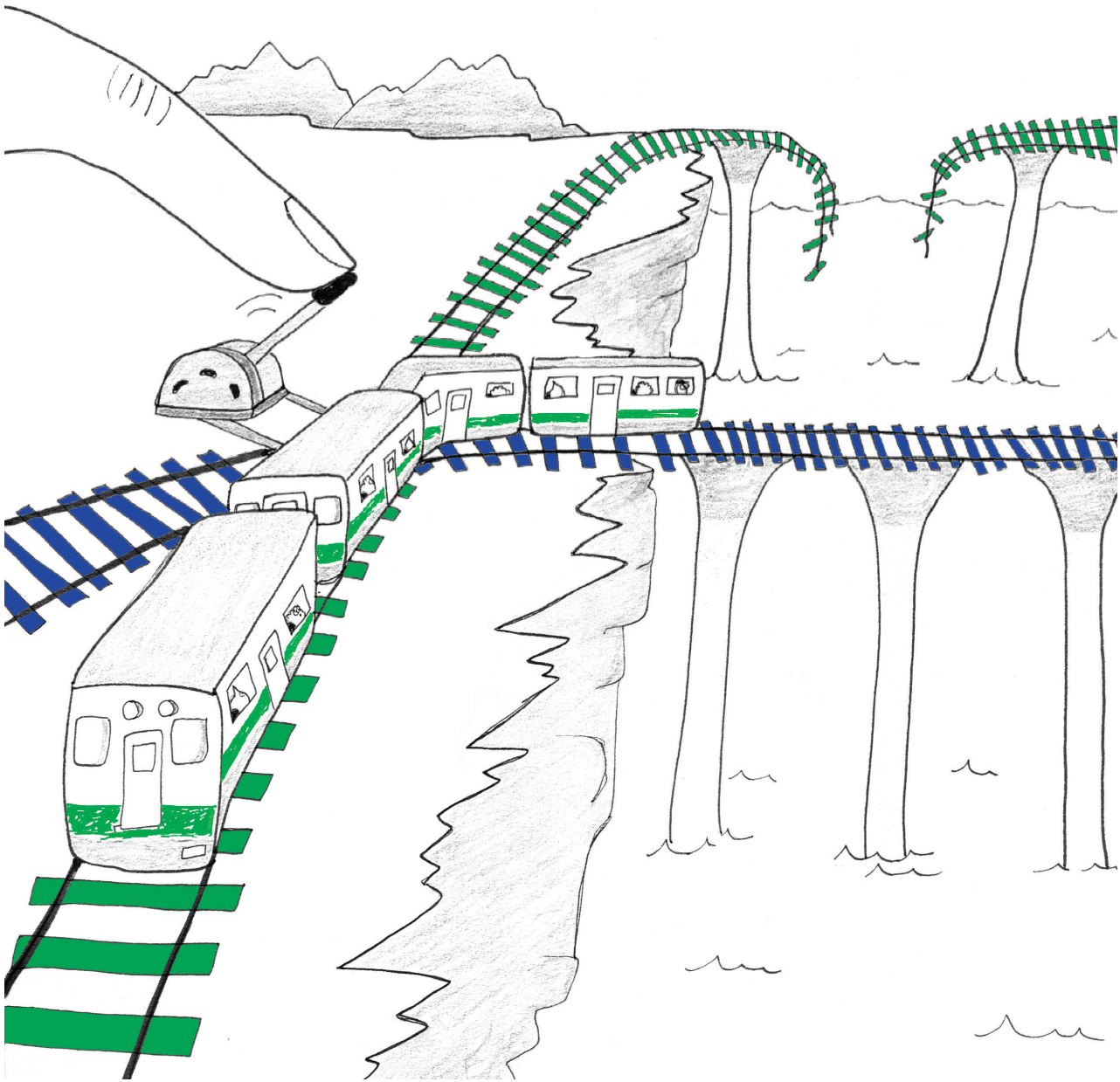
Lymphedema often gets worse over time.
Significant damage to the lymphatic system may not allow for a LV bypass.


DID I FALL ASLEEP? I THINK I MISSED MY STOP.
IS THIS THE EXPRESS?
CHANGE OF PLANS, EVERYBODY!

Now they decide they have to get a working green train and undamaged green train tracks from another part of the track system. They bring these over and rebuild the entire area that is damaged.

*The second physiologic procedure is called a **lymph node transplant**. Essentially, the surgeon removes lymph nodes from a healthy part of the body not affected by lymphedema. The lymph node is then transplanted to the unhealthy area that has lymphedema. Over years, these healthy lymph nodes will grow new lymphatic channels that will improve the patient's ability to clear the lymph buildup.*





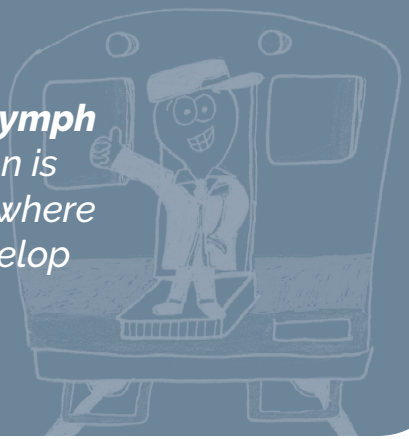
SECTION 4: HOW TO PREVENT LYMPHEDEMA

Let's look at an entirely different scenario and rewind to where the green train has not hit the crack in the tracks yet. The engineer has binoculars and sees the crack coming but can't stop the train in time. *As it turns out, the train can switch tracks before coming to the crack.* The engineer pushes some buttons, and the green train switches onto the blue train track system before hitting the crack. We avoided the disaster!

*An exciting and promising new field of lymphatic surgery is **immediate lymphatic reconstruction.** In patients who are at high risk for getting lymphedema (i.e., patients who will have lymph nodes removed), surgeons are able to perform a lympho-venous (LV) bypass at the time of the lymph node removal to reduce the risk of developing lymphedema.*

The B&L Line is dedicated to having happy passengers and keeping the green train on track!

Ultimately, the goal is to get the patient's lymph back to the heart. *Every patient and situation is different, and a multi-disciplinary approach where your health care team works together to develop the best care plan for you is a must!*



DHRUV SINGHAL, MD is an Associate Professor of Surgery at Harvard Medical School and the Director of the BIDMC Lymphatic Center (Boston, MA). Dr. Singhal's clinical and research focus is in lymphatic reconstruction. Dr. Singhal performs liposuction, lymphovenous bypass, and lymph node transplantation for the treatment of chronic lymphedema. He is a pioneer in immediate lymphatic reconstruction for the prevention of lymphedema in high-risk surgical patients.

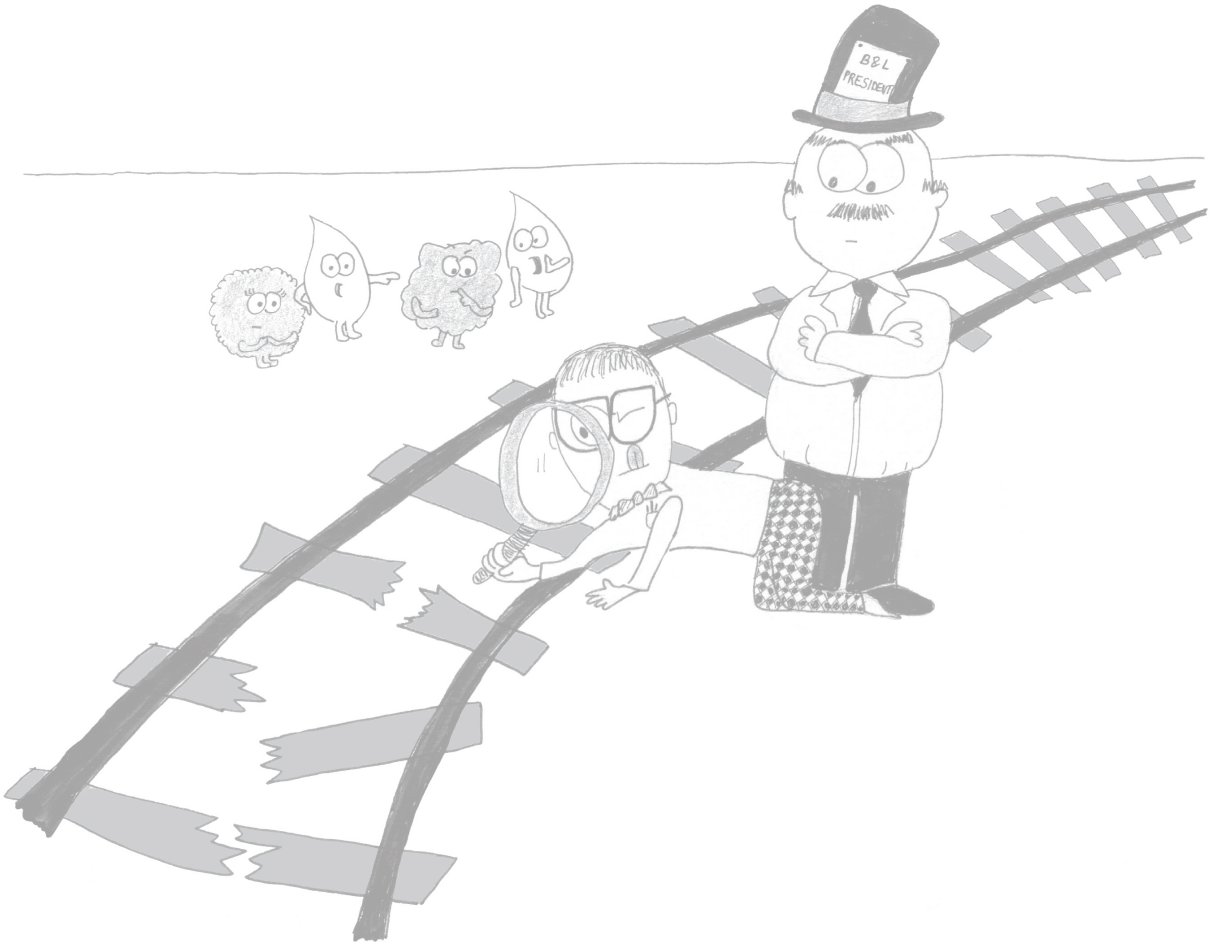
MEGAN BELANGER, LMT, CLT, is an oncology massage therapist and certified lymphedema therapist who has been in private practice in Westborough, MA since 2012. She's also a speaker and educator who has combined her life-long love of doodling with her passion for showing her clients how the body works in her web cartoon series "Under Your Skin." Her website is: www.meganbelanger.com

Lymphatic Education & Research Network

The Lymphatic Education & Research Network (LE&RN) is an internationally recognized non-profit organization founded in 1998 to fight lymphatic diseases (LD) and lymphedema (LE) through education, research and advocacy. With State Chapters in the USA as well as International Chapters, LE&RN seeks to accelerate the prevention, treatment and cure of these diseases while bringing patients and medical professionals together to address the unmet needs surrounding lymphatic diseases, which include lymphedema and lipedema.

Acknowledgments

Megan and I want to thank Bill Repicci and the entire LE&RN organization for the opportunities that ultimately led to this book. We thank Michael Minichiello for taking the time to listen to our ideas and then designing a book beyond our imagination. We thank Ms. Anna Rose Johnson for her critical edits and suggestions.



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