

## Patient perspectives

# Lessons on lymphangiomyomatosis: positivity and possibilities



I was certain it was a heart attack. Pregnant and home alone with my toddler, I suddenly felt pain down my left side and couldn't breathe. During my career in health-care marketing, I had been trained to recognise the signs of a heart attack, but it hadn't prepared me for this moment. So, like any practical person, I packed up my son's dinner to go, ensured the diaper bag was fully stocked, grabbed my laptop, and drove myself to the emergency room. Later that night, I'd learn my heart was not the issue, rather my lung had collapsed. As the intern prepared me for my first chest tube, he warned "grown men often throw punches...or cry"—not great news for this self-declared wimp. I decided the only way I'd get through it was to have fun. It turns out, making jokes about the health-care team packed into the operating room (one medical student really looked like he might faint) was an effective painkiller. I learned something that night: I'm stronger than I think and positivity is a powerful thing. I had flipped a bad situation into a good one; a trick I later named the Flip. The Flip has become the most powerful tool I've ever needed.

Days later, a pulmonologist diagnosed me with a rare disease I could not pronounce: Lymphangiomyomatosis (LAM). My quick internet search revealed a rare, progressive, interstitial lung disease, targeting women in their prime. A disease with no cure, which could lead to respiratory failure and death, with a 5 to 7-year prognosis. My whole world shifted. I realised if I only had 5 years left, a scenario in which my daughter would turn 5 years old without me, I had better make each day amazing. My family quickly adopted a profound appreciation for the little things; we led with kindness and gratitude, and we focused on positivity. We also connected with the *LAM Foundation*, who introduced me to fellow patients (known as Lammies). These brave women showed me that you can choose to let a disease define you, earn you sympathy, and ultimately take you down, or you can flip it, letting it teach, stretch, and empower you. The foundation also connected me with specialists who taught me that the prognosis was likely closer to 20 years and, after a career in health care, I know how much science can change in that time.

I have chosen to love my life, even with LAM. A disease that others would describe as the worst thing to ever happen to them has become one of the best things to ever happen to me. It has shown me great clarity, given me perspective, and helped me uncover my purpose of enabling others to flip bad things into good. I have had my share of medical troubles—five pneumothoraxes, countless chest tubes, pleurodeses, kidney surgeries (one failed, one successful), and so much more. Despite all of this, my lung function is steady, my

lungs look consistent, and I feel better than I have in years. I've made a promise to myself to use the Flip, seeing each setback as an opportunity to reconnect with my purpose. Each moment of daily pain is a lesson about strength and positivity. Each hospital stay is a reminder of the deep-rooted gratitude I have for health-care professionals.

Those who work with patients hold so much power, not only in the life-changing physical effects of their work, but also in the potential to support overall wellbeing through perspective and positivity. Their genuine care of people as human beings is so important, treating the whole patient, and understanding the importance of mindset, attitude, and hope. There are long-lasting physical impacts of this approach. I'm certain that my remarkable disease steadiness, living outside the normal progression of this disease, is because of positivity. I am grateful to have had a 5-year prognosis turn into a 20-year (plus) window; although very few patients with LAM might receive similar news, there are so many ways to help them see the bright side. I challenge all those working in health care to adopt this positive approach in the hope of better outcomes for their patients, for their own wellbeing, and to enhance the impact they have on the world. What if clinicians were to walk alongside their patients after the diagnosis, update, or surgery to better understand the impact they have? What if they focused on generating hope and positive intent in addition to everything they already do? I implore health-care professionals to try this approach out and watch patients thrive.

7 years after that first lung collapse, I'm still here and doing well. In fact, I've doubled down on my purpose in many ways. I've learned that my story can help others both personally and professionally, including inspiring teams at the National Institutes of Health Annual Orloff Awards Ceremony, making a short film about my life to encourage positivity, recording podcasts to spark hope, and coaching people who are enduring tough times. I've even used my story to mobilise companies, brands, and professional teams to take action on making their products more sustainable and socially responsible. Living my purpose has become a fulfilling adventure.

Most recently, I've joined the Board of Directors for the *LAM Foundation*. This small, but incredibly mighty team has already accomplished so much for women with the disease—from building a wonderful community of patients, families, clinicians, and researchers, to ensuring accurate information is available and raising millions of US dollars to fuel important research. The impactful work of this group is utterly astounding. My new role with them has



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*Lancet Respir Med* 2020

Published Online  
February 11, 2020  
[https://doi.org/10.1016/S2213-2600\(20\)30068-0](https://doi.org/10.1016/S2213-2600(20)30068-0)

For more on the **research at SMU using video gamers** see <https://blog.smu.edu/research/2019/05/19/dallas-cowboys-legend-and-video-gamers-help-fight-cancer/>

For an **example of 3-D printing use in medicine** see <https://www.nhlbi.nih.gov/news/2019/researchers-develop-lung-mimicking-air-sac-using-3d-printing-technology>

For more on the **effects of positive thinking** see <https://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/positive-thinking/art-20043950>

introduced me to brilliant, inspiring, and caring people who are committed to improving the lives of women with LAM. It has been a humbling experience and has provided me with an opportunity to use my professional innovation expertise to influence the future of LAM research. Innovation changes the world; it unlocks possibilities and solves big problems. I'd like to see our team innovating in two ways.

First, I'd like to see more research that applies substantially different approaches to curing the disease. Often when I hear about new research, I'm confused as to how it's truly different from what has already been done. Here, my scientific naivety might prove helpful. I sense we've fallen into similar traps that happen in corporate innovation—we've become narrow in our search, exploring the same avenues when the answer might lie elsewhere. I envision a world in which we continue to pursue learning in these familiar areas, but also try new ideas in robust ways. I'm inspired by radical solutions, such as that used by Southern Methodist University (Dallas, TX, USA) researchers who are enabling video gamers to help advance cancer research, or the potential of 3-dimensional printing to create new body parts, and CRISPR gene editing to eradicate disease. There are even simpler potential solutions to explore, such as 81 mg aspirin—an idea I love simply because I mistook my first experience with LAM as a heart attack and the irony would make for a great story. Somewhere out there is a world-changing idea, but we will never find it if we continue mining only in the same areas we've already been. I believe in the power of breadth and depth and advocate for seeking new results by trying new ideas.

Second, I see an opportunity for the perspective that comes with a design innovation challenge. Design challenges are unique in that the team must consider the full experience for those they wish to help—a broader picture than the

disease in isolation. For example, with LAM research, we would supplement traditional cure-seeking research with attempts to improve the patient experience. We would listen to patients, learning what barriers they face, and we would then aim to solve these issues. An internal patient survey carried out by the *LAM Foundation* highlighted several areas in which Lammies struggle: fatigue, body pain, shortness of breath, and anxiety and depression. I am sure these are not specific to LAM and that many patients with lung disease and rare diseases experience these factors. The search for a cure will absolutely help them eventually, but what can be done for them now?

I hope that in writing this, I will encourage readers to learn from my lessons from LAM. First, practice the Flip today—I promise you can do it, and I guarantee it will make life a little better. When you find yourself frustrated or feeling down, ask yourself what's good about this situation? There is always something, you might just have to get creative to find it, and it can be the driving force behind seeing positive mental and physical results. Second, recognise the influence you have on others, be it through your research, your counsel, or even just the contagious side-effects of your positivity. Third, be inspired to innovate in your field whether it be in scientific research, a process you use, or simply how you interact with others. And last, for all health-care professionals, please accept my gratitude as a thank you from all the patients your work impacts. You might not hear it from patients as much as you should, but know that we are thankful for everything you do. Every appointment, every piece of advice, every procedure, and every piece of research that goes toward making the world a better place—please keep going, we need you.

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