

Love, Courage, and Miracles – A mother’s journey and her daughter’s story

An Interview with Robin Modlin by Siri Vaeth

Longtime CFRI community member Robin Modlin has released a moving memoir, **Love, Courage and Miracles**, in which she shares the fear, pain, empowerment, and joy of raising her daughter, Anna, who lives with cystic fibrosis. The following is a brief excerpt; to read the full interview, go to <http://tinyurl.com/bp6rwh95>

You have shared so openly about your life and your family members’ lives. How did this feel for everyone?

I sought permission from everyone before I began. We all agreed that Anna’s story and our life with CF and transplant needed to be told. When I wrote about them, I let them read the writings to be sure they agreed and were ok. We all believe and hope that this story can help others who go through similar situations.

How did you juggle your fears for Anna with your hopes?

We almost lost Anna to CF when she was first diagnosed, so we knew the slippery slope and steep precipice that was always there. Doug (my husband) and I were a team and shared our fears and hopes with each

other, balancing out our concerns. Going to CFRI meetings where Dr. Jeff Wine explained CF and the new research findings helped us a lot. We saw the reality that this disease was extremely serious, and yet we believed that science and medical research would increase hope and lengthen survival.

I also had a spiritual belief that helped to sustain me. I knew we would do whatever we could for Anna, and that her life was precious whether it was cut short or she had the good fortune of living longer than we expected. I believed a voice that said to me, “If she lives a short life there will be blessings. If she lives a long life there will be blessings. They are both the same.”



Anna with her mother, Robin Modlin

What advice would you share with parents who are just beginning their CF journey?

The CF world is very different now. The modulators are revolutionizing care and survival statistics are phenomenal, yet I know that a diagnosis such as CF can be a terrible

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Paul Bollyky, MD, PhD and Kevin Qingquan Chen, PhD

Targeting Bacterial Resistance to Phage Therapy in Cystic Fibrosis

Paul Bollyky, MD, PhD

Despite recent progress, lung infections remain a critical problem for people with cystic fibrosis and their families. Antimicrobial resistant (AMR) bacterial pathogens, including those caused by *Pseudomonas aeruginosa*, continue to cause chronic airway infections in CF. Oftentimes these are polymicrobial (caused by more than one bug), magnifying the challenge. We need new therapies and approaches for tackling these challenging infections.

“Phage therapy,” the use of viral pathogens of bacteria to kill bacteria, is a promising therapeutic strategy to treat multi-drug-resistant bacterial infections. Moreover, phages are highly selective and only kill their particular bacterial host, making phages safe and less

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shock. I would say, first feel the loss of safety that the diagnosis can cause and allow the grief that will come up. Next, know that our fears are just that, our fears. They do not determine the eventual outcome. Begin to look for how CF is providing an opportunity to be a part of a committed community, and a life challenge that will help you grow as a person. It is up to us to accept and use this experience in a way that is beneficial for the community, our family and ourselves personally.

Share with me the importance of humor in coping with chronic progressive disease? It sounds like it is Anna's superpower!

Humor is one of Anna's superpowers for sure. Humor helps you to stop fixating on the causes of your suffering. It is not funny to feel the grief and pain that can be caused by a chronic progressive disease but making light of some of its effects or situations it puts you in can elevate the moment.

I appreciated hearing about Anna's sister, Sara, and her hidden grief, chronic sorrow, and "proactive survivor's guilt." What would Sara say to siblings of people with CF?

Sara always wanted to connect with other siblings who could understand her experience. She wanted to know if what she felt was common and for her experience to be acknowledged. I believe she would encourage other CF siblings to open to their feelings of fear and loss and share them with whomever they trust. She would want to tell them that this is a very difficult role to play in a family. To be the one who is considered to be the survivor and to watch the challenges of their sibling is fraught with complicated emotions. If it feels overwhelming it is good to seek counselling.

Tell us about your entrance to the transplant community, where hope, joy and grief coexist.

When a CF patient receives a lung transplant, they and their family enter a new door. CF takes a back seat as surviving the surgery and immunosuppressants becomes primary. If it is a successful transplant, what is witnessed is nothing less than a miracle. The world of transplant introduces you to people who have survived their impending death and are reborn with another chance



Robin Modlin with her two daughters Sara (l) and Anna (r).

where there are no guarantees but each day feels more than ever as though it is a gift and a miracle. Some donor families also become active in the community. The organ recipients offer them meaning and support by showing their gratitude for life itself. It is truly a remarkable world to be a part of.

You write, "I was learning we were on a remarkable adventure that was unique and good despite the difficulty, Anna's suffering, and our fear of loss." How did your perspective shift?

During the time when Anna was just a toddler, on life support and first diagnosed, I clung to the medical interventions that were saving her life. I did not feel at the time that we were on any great adventure. It was after, when her life was saved, and I could feel what a miracle it was to have a second chance to be able to be her mother. Gratitude and a new perspective filled my experience. I saw that I could take this opportunity to be Anna's mother, as fragile as her life was, and use that experience to grow as a person and be engaged to help others too. It became a grand adventure with learning about acceptance, life and death, miracles and hope.

Being Anna's mom is still a source for learning more about me, how I can live, be

better as a human and open to new experiences. And the greatest miracle of all is our granddaughter, Zoe. Who would have ever, ever thought that would be possible?

Love, Courage, and Miracles is available for preorder.

To learn about meeting the Dalai Lama; hunting for Chinese herbs in San Francisco; waiting for Anna's new lungs; and the surprising life turn when Anna married, moved to Australia, and became a mother, go to www.robinmodlin.com.

