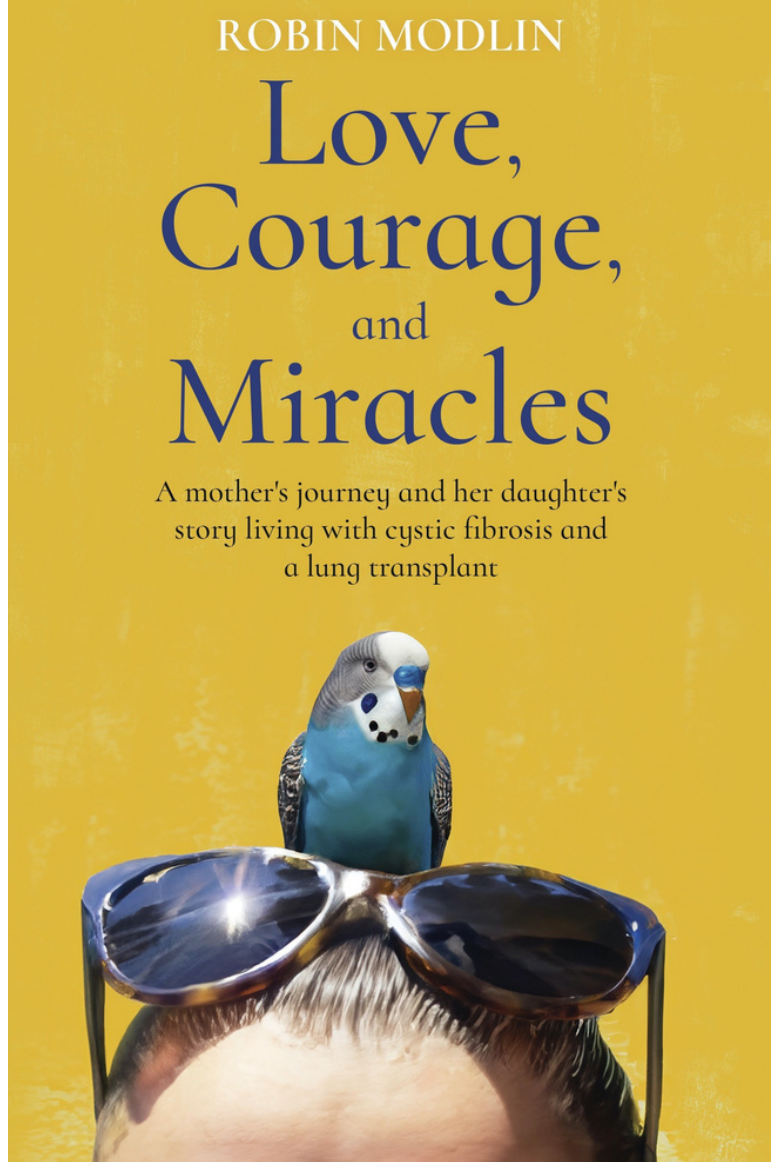


An interview with Robin Modlin by Siri Vaeth

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.



When did you first decide to write this book? Did anything hold you back initially?

Fall of 2022 was when I felt a strong impulse to write the book. I had read a novel that was a collaboration between two authors and could see a path to Anna and I writing together. I jumped into writing right away. Anna agreed to also write but as it turned out, she had too much on her plate to put in the time required. After a few months the story became primarily about my journey being Anna's mother while telling her story and how our lives were woven together.

Tell us a bit about the title.

At first the title was considered to be Miracle Collectors, Miracle Collecting or Chronically Miraculous. When the arc of the story was completed, I saw it was much more than about miracle collecting. One day with my dear friend, Sue who is also a CF mom, I explored with her about what the title should be. Together we saw the story was about, the love in our family, and the courage it takes to live this life. It was also clear that what was special about our CF story and Anna's life was our experience of what we called miracles. That summed it up. The book is about our life journey of Love, Courage and Miracles.

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The path to Anna’s diagnosis contained a bit of serendipity, in terms of the people you met who would become pivotal to your journey. Was this an early miracle?

At the time of Anna’s diagnosis there was a strong feeling that the stage had been set for us to step upon this path with amazing support. Not mentioned in the book, we were also supported by the physicians I had worked with when I was a clerk in the neonatology office before Anna was born. We consulted with these physicians and they checked in on us as we struggled to find an answer to her extreme illness. And then, as I shared in the book, already knowing Dr. Moss and having met the Wines before the diagnosis we both shared was remarkable. Those early connections felt magical, meant to be, and yes, I would say, an early miracle.



What was the importance of your connection to others in the cystic fibrosis community, most notably the mothers?

It was amazing that we had a strong community of other families who lived near-by when Anna was first diagnosed. Most of these families became engaged in CFRI, volunteering and contributing to build our community by fundraising and educating ourselves about CF research. We all knew the stakes and risks for our children. We were all honest, scared and hopeful at the time as CF research was beginning to expand with a growing understanding of the disease and a hope for new treatments. We could enjoy each other as friends and support each other with compassion and understanding that other friends and family members did not have. Knowing moms, comparing notes, asking each other for help, and being in it together was very important to how I coped.



How did you juggle your fears for Anna with your hopes? Did she express her fears to you?

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 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 by witnessing members of our community lose their lives 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 did not know what Anna's future would become but I knew we would do whatever we could for her and that her life was precious whether it was cut short or she had the good fortune of living longer than we expected. I trusted and believed she had her own story to play out. I did not know what that was to be but I believed as a voice said to me in the beginning, "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, had a difficult time sharing her fears with us. We were very blessed that she had many close CF friends and went to CFRI's CF Camp and Adult Retreat where she could participate in rap sessions and openly process some of her feelings with her peers. Anna's initial trauma of illness when she was a toddler was significant and influenced her coping style. To this day she is working on the many traumas that she has experienced due to this disease with a trauma therapist.

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. It is wonderful, yet I know that a diagnosis such as CF can be a terrible 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. There is so much hope and understanding now for these children and that will continue to grow. Once you have accepted that CF is here to stay in your life begin to look for how it is providing an opportunity to be a part of a committed community, and a way to engage in 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.

You share your pain when Anna was intubated as a toddler, and she cried for you to make it stop. You say it is still a “vivid haunt” for you, as you lost all maternal control to protect her. What would you say to other parents who are witness to their children’s medical trauma?

I would say, this is the hardest thing you will ever do and, yet you can do it. You can meet the challenge. You may find that there is strength in you that you have never realized you had. A parent’s love for their child is profound and is the essential ingredient to being able to make it through whatever the outcome.

At the time of the trauma as it occurred in our life, it was important for me to be present and engaged in any way that I was allowed. This included playing music, talking to my baby and letting her know I was there, along with just being there to ask questions of the medical staff, and helping to care for her with things like bathing. I also took walks and did my best to care for myself. I never blamed myself for what was happening with Anna and I tried my best to see clearly that with what was happening, I needed to simply accept. It just was what it was. It could not be changed and we had to deal with it.

Anna was raised with Western CF medical routines as well as “mysterious, magical, miraculous” complimentary therapies. Does Anna still follow a blend of Western and alternative medicine

Yes, Anna follows the same treatment model that we set out for her from the beginning. Anna has always been very compliant with her Western allopathic medical care. She understands her medications, her many disease processes that she has to deal with all of the time, and is diligent with her care. She speaks up with her physicians and lets them know she is a knowledgeable and smart patient. She also includes acupuncture regularly, and engages energy and intuitive healers, receives regular massage and psychic readings for her self care. She tries to touch all of the bases.

Anna believes in the power of her own mind as an important part of her longevity and future survival. She is doing everything she can to extend her life. The alternative therapies and her belief in miracles, magic, and a positive mental attitude support her immune system, offer pain relief and creates the emotional and spiritual support that is critical for her.

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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. For instance, a lot of bathroom humor arises from the experiences of those with CF. Joking about their faulty digestion and mucus production is very common and can create camaraderie and help shift a difficult situation to one of acceptance.

Anna often as a child and still as an adult looks for what she can do to turn around a depressed mood with spontaneous, unexpected behaviors that help us as her family break through seriousness and laugh with her. Her husband, Terry is also good at this important coping strategy. Humor is regarded with many psychological and medical professionals as a good and necessary component to coping well with stressful situations.



I appreciated your words about Anna's sister Sara, and her hidden grief, chronic sorrow, proactive survivor's guilt, and her resulting need to never make waves or complain. What would Sara say to siblings of people with CF or chronic disease?

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

whoever 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. Speaking your truth is the way to gain more understanding and to develop your own self-worth. Do not doubt your own aspirations for your life and go for them.

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." Tell me more about this. How did your perspective shift?

During the time when Anna was just a toddler, on life support and first diagnosed, I clung onto 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.

Continued on next page.

Gratitude and a new perspective filled my experience. As I tell the story, I was a woman who was very introspective and interested in my spiritual life. The experiences we had of meeting a Tibetan lama who supported our healing after she came home from almost dying, looking for other means to offer her healing, having excellent medical care and frankly finding an intelligent and supportive community of other CF families were integral to forming a positive perspective. 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.

Tell us about your entrance to the transplant community, where hope, joy and grief all 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. An unknown person who has quickly met his/her demise serves as a savior. They and their family are considered heroes. The world of transplantation is where you feel a deep and incredulous joy and immense gratitude because of this miracle gift. Even so, it is a rough and tough road that is only for the courageous.

The world of transplant introduces you to people who have survived their impending death and are reborn with another chance where there are no guarantees but each day feels more than ever as though it is a gift and a miracle. Some donor families who have lost their loved ones but donated their organs so another could live also become active in the community. These people carry their grief and loss with dignity and hope. 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.



“Our journey is still attached to her journey.”

How have you reconciled Anna’s move to the other side of the world? Where does this fit with the miracles in your life?

At first when it was clear Anna truly was moving forever to Australia it was very difficult for us to accept. It “blew our minds” as one would say. She had already “blown our minds” with other choices she had made and her amazing accomplishments after transplant, but this was the “kicker”! We had to quickly catch up to her new reality of becoming an Aussie and us as a family without her nearby.

First of all, I trust Anna. I trust her ability to take care of herself with her strong intuition and very smart mind. She researched if this move would be a benefit or hinderance to her medical care. The lung transplant care at The Alfred medical center in Melbourne is considered among the best in the world. She was confident she would receive the care she needed. She was also deeply in love. The relationship between Terry and her happened quickly but it also did with me and her dad. Her intuition about their marriage gave her visions that I share in the book. They foretold deeper reasons for her to make the bold move.

I know Anna and how courageous she is and this decision required her to wholeheartedly buy in. We had to respect and honor her and this decision. Doug, her sister, Sara and I just had to catch up to it. I had a daughter whose life was almost lost more than once and whose destiny was pointing to a surprising and unexpected place. It made us deeply uncomfortable and we wished it was not happening that way. Loving Anna dearly we just had to grieve our loss of her being close, let her go, and simply celebrate her new remarkable life.

Our journey is still attached to her journey. As much as I resist and get crabby about having to travel, I pull myself together and do it. Being in her Aussie world is still filled with the amazing and miraculous. We now allow ourselves business class to fly! It makes all of the difference. 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?

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. We also believe that people are curious about what CF is like or what transplantation is like and are proud for others to know our story.

How are Anna and her family today?

Anna is now officially an Australian citizen and that is no easy feat. Her health has had many challenges in the last few years. She is a full-time patient and receives excellent medical care. Currently she is fighting a mycobacterium infection. We recently visited to support her as she started a new treatment of IV antibiotics every day, three times per day for many months to come. She has had to reorganize her life to make this work. She is the mom of a three-year-old child, Zoe, and has many disease processes due to her CF and transplant that she has to manage like her CF related diabetes and need to gain weight. At times it seems so daunting, but Anna has risen to the occasion as she always does. She is figuring it out in a very positive way making time and room for her acupuncture, massage and mental health.

Zoe is growing up with a mommy who is wonderful, loving and giving. Zoe is truly a clone of her mom when she was little with that cheeky sense of humor and interest in playing with dolls and miniatures. She also is learning about how Mum has to go to the hospital for days at a time and receive nurses into the home to help her with this IV treatment. Zoe knows how it goes. Her daddy, Terry is loving and supportive and adds his Aussie humor into the room helping everyone. Zoe's other grandmother, Rhonda lives nearby and has become an important part of their support system. I am so grateful for the care, love and time that Rhonda is giving to them. Anna needs support and she is making sure she gets it.

Not a question, just a comment: I loved reading Anna's journal entries as she waited for her lungs to arrive. They are a gift to all of us.

Agreed! I felt it was very important for Anna's voice to be a part of this story.

Love, Courage, and Miracles

(Atmosphere Press) will be released in May, 2024. 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, preorder your book today at www.robinmodlin.com

Love, Courage, and Miracles

A mother's journey and her daughter's story

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