

Rare: One Family's Faithful Journey Through Cancer

When we started down this path, a path that we were not mentally or physically prepared for, our first feeling was one of complete disbelief—cancer—not our family, not our child.

As parents, Nancy and I always believed we knew what to do for our children, and we now were faced with a situation over which we had no control. That was and to this day still is the worst part of going through cancer. You wake up and go to sleep feeling that you should be doing something, but you are not sure what to do. As parents, we always believed that we should and must protect our children. Now we were faced with knowing that in this situation we were not able to protect Rebecca. As her father, this was the worst part.

Rebecca and I had talked about our goal to write a book some day. I am sure many of you have thought about writing a book as well. Many ideas came to mind but have always lacked a real deep- down passion to start writing. Now, for the first time in my life I had something to write about that I was passionate about. This is a story about our family's journey down a path of uncertainty that was filled with newly found faith.

When we talked about writing this book, we wanted to tell this story from the many perspectives of the people who had touched our lives on this journey.

I also believe it is important for cancer patients to understand how their loved ones are feeling and to understand the effects on them, as well. Rebecca and I talked a lot about feelings: hers, mine, her mom's, her brothers', her friends' and so on. I think it helps us to have a better understanding of life when we think of it from another's perspective: a

simple concept of empathy. I know it helped Rebecca and me.

Rebecca's cancer involved many people who have supported us. There were many times I knew that Rebecca was not aware of my feelings like when she was in surgery, recovery, or as we have come to call it, when she had "chemo brain." Even though I was there with Rebecca, there were some innermost feelings Rebecca did not tell us about.

Rebecca's story will be told from the perspective of her friends, family, diary excerpts and emails based on how she felt at the time. This has provided me with insights into her innermost feelings. It was critical in writing this book to understanding all her feelings and presents her side of the story.

Lastly, we wanted to express the feelings from our family and friends who have been with us, sharing our tears and laughter. Yes, we have laughed a lot—even about Rebecca's cancer: That is just the way we, as a family, have always handled the life situations that have been thrown at us.

When we asked family members, friends, doctors and health care professionals to give us their perspective on Rebecca's story, we did not share anyone else's writing to keep each one's own special message unique. One reason we wanted to tell this story is to let other families know how many people in this world care about them. In Rebecca's case, there have been thousands of people affected by her cancer and that truly has been inspirational.

The Why of Our Book

In talking with other families who had cancer suddenly appear in their lives, we noted a lot of similarities in all our situations. It was in these similarities and hardships that we felt there were lessons to be learned for the next generation who will face this disease without notice and without any knowledge as we did. The essence of this book lies in our

compassion and belief that if you go down the path called cancer, then you must help the next generation and other families to understand and learn from your experiences.

Our goals are simple: to provide our gained knowledge about Rebecca's cancer treatment, to tell our family's story, to share some tears and laughter, and to talk about our faith, because it was our faith that enabled us to get through this.

Nancy's thoughts about the book are ever so emotional and honest as a parent. "The most unnatural thing in the world, as a parent, is to watch your child become sick and die. When I read this book, detail by detail, I thought to myself, how did these parents go on after this beautiful girl's life? I have to stop myself for a split second and realize that Rebecca was our beautiful daughter and we are those parents."¹

Faith

Our faith-filled views are interwoven throughout this book to better prepare others whose lives are suddenly turned upside down. There is no magic pill like the one Becky once asked the doctors about.

For us, our faith has held us all together, and the truth is that we are all now closer to our faith. It is one of the many gifts we have received from this experience. I know it is strange to say that we have received a gift, but now I have come to the conclusion that we were guided down this path with a specific purpose. I was not always sure what that purpose was, but we collectively always felt God's love near us.

When asked how our faith is today, I simply answer, 'the same as always'. We trusted in God's plan, then and now. Dr. Neil Finkler was Rebecca's oncologist. The words in his reflection about Rebecca help bring an understanding about our family's faith as he witnessed it first hand.

Dr. Neil Finkler

“Perhaps the most remarkable aspect of Rebecca and her family was their deeply held religious beliefs which, in the end, carried all of them through this horrific illness. I was amazed to see someone of Rebecca’s age with such unflappable faith. I could always understand a deeply-rooted faith in people of my age but thought these kinds of unconditional beliefs would crack in a younger person facing such an illness. This never occurred. Rebecca knew where she was going and smiled through it all. Her calmness even in the last few days of her life bore testimony to her unshakable religious beliefs.”

In Conclusion

Many of us were raised (at least I was) with the understanding that when cancer affected your family, you kept it a secret, and it often was not even discussed openly among family members. When we started this chapter in our life with Rebecca, we made a decision as a family to be very open about our story and to share our innermost feelings. To my amazement, I have been thanked by so many people for sharing my feelings, my concerns and my love for Rebecca that, at times, I have been overwhelmed by others’ responses. Because of our openness, so many people have shared intimate details that have affected them on their life journeys, and I have been blessed to know each one of them.

There is no way to thank all of you. My ability to be able to complete this story is based on our collective love for each other and from the many late night phone calls and support from my family, friends and co-workers. I think by being such an open family we surprised some people, but that is what we believe in. As Rebecca had said simply, “We are all inhabitants of one planet, and we are all interconnected.” To share our family’s story is what we are supposed to do.

It is also important to acknowledge the people who have agreed to be a part of this 19-month saga. This book is extremely

personal to me and to the individuals who contributed their thoughts and feelings in regard to their interactions with Rebecca. The individuals who are quoted have reviewed the book, but I have not requested that the book be reviewed by any institution or healthcare facility.

It was never intended and not expected that any person whose statements are quoted in the book were expressing any views, positions, policy, statements or opinions on behalf of any institution, facility or any other person. Therefore the statements, thoughts and feelings expressed in this book should be considered as the personal statements, thoughts and feelings of individuals making the statement and do not represent the views, positions, policy, statements or opinions on behalf of any institution, facility or any other person. The individuals in this story are all real and their names are used with their permission.

*Note: The preceding is an excerpt from **Paul Stepusin's** book, "Rare, My Daughter's Faithful Journey Through Cancer," from Paul Christopher Productions. Stepusin writes how faith was found through his daughter while she suffered through the worst phases of her cancer. The book can be purchased at .*