SPRING 2023 | ISSUE NO. 4



HEROES AND MAGIC

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Crews

EDITOR'S NOTE

Editor's note

by Dana-Susan Crews

Not a lot of people know this, but when my son Dylan was 12 years old, we discovered a lump in his abdomen. It didn't seem very big and we thought it was mobile, but to be safe, we made a call to my husband's oncologist.

Because of Bill's cancer and our family history, his oncologist told us to get in our car and drive to MD Anderson Cancer Center where he was scheduling Dylan for an appointment with a pediatric oncologist. Amazingly, he got him on the schedule right away and within an hour, we were walking into the children's hospital there.

It was not my first time to be there. Although Bill had been a patient at MD Anderson by then for a long time, we rarely had any reason to visit the children's hospital, but I had gone a few times with the development department as a donor. But this time, we entered with our 12-year-old to find out if he had cancer. We did not believe his lump was malignant, but if there was any chance at all that it was, we needed to be in the best place on Earth to get it treated.

I think everyone should make a visit to a children's cancer hospital and get a first-hand look into the devastation. It would put the troubles of life into some perspective.

The children's hospital at MD Anderson is beautiful. It's lively and colorful and very warmly inviting. The people who work there and volunteer there are kind and calm and gracious. No one wants to see their child become a cancer patient, but if that happens, how great is it that places like these exist! It takes a true calling to work in oncology at all, but especially pediatric oncology.

We sat in the waiting area for only about 20 minutes before Dylan was called back. I saw sights I've seen many times in my life. I saw children in masks (long before Covid-19). I saw children in wheelchairs. I saw a teenager vomiting on her mom's lap. I saw a little girl wrapped in a blanket holding her dad's hand. They were bald and sick and some of them were knocking on Death's door. It was not ok.

But as I had seen many times before both at MD Anderson and at Texas Children's Hospital and other institutions over and over, I also saw strength and hope and faith. I sat there praying for God to help these kids and their parents and their families. And I prayed for those people who work there. From the receptionist to the scheduler to the nurses and the doctors and all the volunteers, I prayed for their strength and hope and faith.

When Dylan was called back, the oncologist was amazing. He talked to Dylan in such a comforting and even fun way. Dylan really seemed to like him and felt very comfortable talking to him. He wore a colorful tie and a smile that put us all at ease.

A couple of days later, Dylan had surgery to remove his lump which we discovered was about the size of a golf ball, but thankfully, benign. The whole surgical team was incredible. They made Dylan feel safe and secure and they kept Bill and me calm. We couldn't have imagined feeling more confident as they wheeled our son back for surgery.

I love pediatric oncologists and nurses and everyone who works with kids with cancer. They are heroes and champions and I am very grateful for them all. Crews Editor's note

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Speaking of pediatric oncologists, I would like to introduce you to one of the greatest that the world has ever known. I was honored to meet him years ago at a screening of the documentary film "Cancer: The Emperor of all Maladies".

Dr. Emil J. Freireich was born in 1927 and died on February 1, 2021. His legacy lives on in the lives of every survivor of childhood leukemia.

When he came onto the scene in the early 1950s, every child diagnosed with leukemia died. In fact, they bled to death on gurneys, usually within a month after diagnosis. Dr. Freireich worked with IBM to develop the very first machine that could separate platelets from the blood to be transfused into patients to keep them from bleeding to death.

He also believed that kids with cancer could be treated with a combination of chemotherapy agents and thanks to him, patients even today are doing this combination therapy. He personally was a part of seeing childhood leukemia go from a zero chance for survival to the 85% chance for survival that it is today.

When I tell you that I met one of my heroes, I do not mean a rock star or a Hollywood actor. I mean a real hero. I will always cherish the hug he gave me and I will remember him for the fact that his hard work and love for kids have saved countless lives over the decades. Thank you, Dr. Freireich and all of the great people who work in pediatric oncology!



Dr. Emil J. Freireich, 1927-2021





Not all heroes wear capes. Some wear lab coats!

In Honor of the Doctors and Nurses of Pediatric Oncology...





"There is a very good chance she could die. I'm going to use all of the tools in my tool box. It is going to take all of the tools in my toolbox but I am going to try and not just save her but cure her." ~ Dr. Daniel Zinn

"Because of Dr. Zinn, our daughter is still here." ~ Warrior Mom, Shari Ann Almeida





When then college student Kylee McGrane-Zarnoch decided to dress up like a princess one day and go visit kids in the hospital, she could never have imagined the magic that would happen and that her idea would soon become a national movement, touching lives across the nation.

It all began in December 2014. Kylee and her roommate Margaret McAndrew (Maggie), recognizing that no other organizations were doing this, began raising funds and purchasing costumes. They began by visiting kids in hospitals in the New York area, but by the Fall of 2015, their tiny idea had sparked some true magic. Overnight, the two ladies suddenly expanded to 40 college students who were committed to visiting children in hospitals all along the east coast.

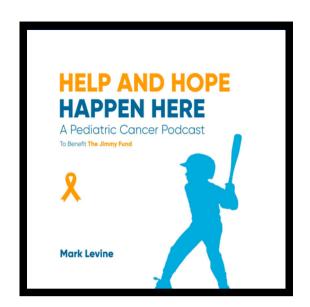
Soon, Kylee and Maggie learned much more about pediatric cancer and its gross underfunding. They learned about the harsh treatments kids are forced to endure and they began forming close bonds with the kids they met. They knew that their little idea of spreading magic to these kids needed to grow.

And grow, it did. One year later, A Moment of Magic's story went viral, grossing more than 65 million views worldwide. Today, they have chapters on college campuses all over the United States. College students dress as princesses and superheroes and bring much-needed magic to kids in hospitals. They offer in-person creative programming, virtual creative programming, and direct family support to the kids and their families.

Kylee has written a beautiful book, "Your Magic" which will be published later this year. To know more about her and this incredible organization, please visit www.amomentofmagic.org.









HELP & HOPE HAPPEN HERE

a podcast all about childhood cancer

For almost three years, the childhood cancer community has listened in with great loyalty and anticipation to a podcast that focuses strictly on pediatric cancer. That kind, compassionate voice has become quite recognizable and so popular now that when we hear him, we think about kids with cancer immediately.

Mark Levine and his podcast, "Help and Hope Happen Here" began in 2020 and with now more than 200 episodes, it is stronger than ever. Mark has given a powerful voice to the families dealing with childhood cancer and he is nowhere near stopping.

Mark began his journey in 2008 when he got involved with the Jimmy Fund Council, the fundraising arm of Dana Farber, to raise funds for both childhood and adult cancers. "A couple of years after I joined," he said, "I decided that I was most interested in pediatric cancer, so I decided to start an event called 'Putting for Patients' which is a mini gold fundraiser which I brought to various high schools in the Greater Boston area."

When the pandemic struck in 2020, Putting for Patients, a student-led fundraising event, had to cease for a bit. That is when Mark decided to take his passion to the masses with a podcast all about childhood cancer.

"My goal was to interview people who were involved in some aspect of Pediatric Cancer and raise awareness for a cause that I consider to be the most important cause in the world which impacts far too many children and their families," Mark said.

Mark interviews childhood cancer patients and survivors, their parents, their siblings, pediatric oncologists, people who operate nonprofit organizations, and so many who are involved in advocacy and fundraising for diseases that no one should have, especially kids.

His wife Debbie is the technical support working behind the scenes. She makes sure each episode is uploaded and operates smoothly. Together, they make quite the team, bringing listeners incredible stories each episode.

"So many things have struck me during the past 2 ½ years I have been doing these podcasts," Mark said, "I would say the most interesting things have been meeting these incredible people, whether they be parents of children going through this fight, recovered patients, oncologists, heads of foundations, researchers, and many other people from different facets of Pediatric Cancer. The other thing that has been truly amazing is to interview young people who have decided to get involved in this cause as advocates and the way that they are committed to helping others. I can most definitely say that each person I have spoken with brings a lot to the table and they are all to be thanked for what they do, and thanked for taking the time to speak about it with me."

Mark and his wife Debbie have two grown sons and two grandchildren. In his free time, he enjoys running, watching football, and being with his family. Find this amazing podcast on Apple podcasts (a link is also available at www.bellasteri.com/resources).

Cash's Corner SPRING INTO ACTION

In this month's edition of Cash's Corner, since this issue is all about HEROES, here are some fun ideas kids and families can do together to raise funds on behalf of childhood and adolescent cancers. Everyone has the ability to make a change!

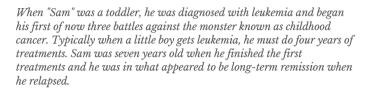
FUNDRAISING IDEAS FOR KIDS AND THE WHOLE FAMILY

- Lemonade stand you have probably heard of Alex's Lemonade Stand and if not, do a search today because you will be inspired! Did you know that you could set up your own lemonade stand in your neighborhood and raise funds for childhood cancer? Make some lemonade, decorate your table, sell lemonade to your neighbors and donate all the funds to help bring an end to childhood cancer.
- Bake sale whether you do this at home, at a hospital or school or even at a church, get some friends together and host a bake sale with all of the proceeds going to fight childhood cancer!

- Party host a party either for your birthday or Easter or just for fun and invite your guests to bring a donation to childhood cancer.
- Gold ribbons buy gold ribbon at a craft store and make gold ribbons for childhood cancer awareness and sell them as a fundraiser.
- Gift baskets money for research isn't the only thing you can bring in. Get people to donate items like socks and blankets and stuffed animals and books and put together lovely gift baskets to take to kids in the hospital. Be sure to write an encouraging note to let the child know you are thinking about them.

A NOTE ABOUT BEING A HERO

the following is from a teenager who is a three-time cancer warrior



At the age of nine, his leukemia returned and became very aggressive and he had to undergo very aggressive therapy which included permanent damage to some of his internal organs and scars on his face that will never heal. Thankfully, he was free of disease for a long time until he turned 18 and discovered that once again, cancer wasn't finished with him. Currently, he is fighting not only a terrible cancer, but complications from a life filled with poison being pumped into his veins.

Sam does not want to be identified. He just wanted to share a perspective that not everyone understands about growing up with cancer and not getting the chance to be set free...

"I don't know what it is like to be a normal kid. When I was little, I didn't get to have a pet because my doctor said they bring in too many germs. I didn't get to go outside and ride my bike with the neighbors or my brother. I didn't get to go to school. Other kids complain about going to school. They have no idea how much luck they have to get to do that.

I had two years of not having to do treatments. That was great. I got to go to Disney. I got to play outside. I got to get a dog. I went to a real school. But then it all got taken away from me again when my cancer came back. I was in the hospital all the time. I was sick all the time. I was depressed. Sometimes the only reason I fought to live was because of my parents and not wanting them to be so sad.

I barely made it through that second fight with leukemia. My whole body took a beating and it changed my physical appearance permanently this time. I don't like looking in the mirror. I look way older than I am.



One of the things I have a hard time with is having people call me brave or strong or a hero. I am none of those things. I am a teenager who should have graduated from high school and gone to college. I should have had a girlfriend and I should have gotten to play sports. I should have gone out to parties and gotten grounded for missing my curfew. I should know what it's like to just be a normal kid, not a hero.

I don't get mad when people call me that, but sometimes I wish they would stop looking at me and seeing cancer. I wish they would look at me and see an athlete or an artist or a musician. But they look at me and see a disease.

I am not writing this to tell you kids with cancer shouldn't be called heroes. But I do want people to know that none of us just wants to be thought of as a cancer kid. And even if you think I am a hero just because I have cancer, let me tell you that the real heroes are my parents and my doctors and the people who donate to cancer research. Those people have a choice to do great things, but I don't have a choice. I just had the bad luck of getting cancer.

Don't feel sorry for me. I don't. I just wish I had a different life. Some kids grow up and do great things in the cancer world and maybe I will beat cancer again and do that too. But today, I am just very tired and I don't feel like thinking about that. I just want to be done being sick.

Thank you for letting me get this off my chest."

Sam and his opinions matter. They might be different than yours, but every person with cancer has the right to feel however they feel. Sam is tired and overwhelmed and his story is being shared anonymously because that is what he has chosen. Originally, we reached out to his mom asking if he wanted to publish his story as a book. She told us that Sam doesn't want to talk about cancer anymore. We appreciate him and his voice. His life matters. Although his name is not really Sam, when you think of him, all his mom has asked is that you pray for his healing in spirit, mind and body.





Bella Boxes and Custom Books are our newest projects at Bell Asteri.

Bella Boxes are gift boxes you can order for a caregiver whose spouse has cancer or a child whose parent has cancer or a child whose sibling has cancer. Each box includes a journal, a blanket, socks and other items to help them endure a cancer

diagnosis.

For children with cancer, we direct you to Leia's Kids Foundation and for parents of children with cancer, we direct you to Warrior Moms United by Pediatric Cancer (read more about these organizations on page 11).

Custom Books are children's books that you create alongside our creative team. These 8X8 hardcover books can be anywhere from 20-30 pages in length and can include photos, artwork, stories, activities and more. You can order one book or several books.

Proceeds from Bella Boxes and Custom Books are donated to pediatric cancer research. To know more, visit www.bellasteri.com/products

ORGANIZATIONS

Leia's Kids leiaskids.org

*If you have a child with cancer, please visit this organization's site and get a "My Battle Plan Journal" to help your child get through treatments.

ABOUT LEIA'S KIDS

Many of us know local children and families that have been affected by childhood cancer. Doctors and nurses work hard to cure patients' cancers, but families need more than medical help to get them through this difficult time. This is the point at which the Leia's Kids Foundation intervenes. The foundation provides direct support to children and their families who are facing the often overwhelming childhood cancer pathway.

Leia's Kids honors each child and their family through a Crown-A-Kid party. This is a time to celebrate and encourage the child and family in the biggest battle of their lives.

Each child receives a \$1,000.00 donation from the Leia's Kids Foundation. They also offer emotional support and connect families together to form a community. They walk with families because they understand what it's like to have a child with cancer.

Leia's Kids focuses on the whole family because cancer affects everyone! (Sometimes fighting cancer comes in the form of doing the dishes or babysitting your younger siblings while mom and dad are at the hospital).

Please visit www.leiaskids.org to order a journal for a child you know or to donate so that Leia can keep this mission moving forward.

Warrior Moms United by Pediatric Cancer warriormomsunited.com

If you are a parent of a child with cancer, please visit Warrior Moms United by Pediatric Cancer (which now also includes Warrior Dads) and get some much-needed support as you endure this great war on cancer.

ABOUT WARRIOR MOMS

Shari Ann Almeida understands the devastation of childhood cancer and its profound impact on parents. When her own daughter was six months old, she was diagnosed with leukemia and this forced the family into the toughest season of their lives.

Warrior Moms (and now Dads) helps parents of childhood cancer patients feel seen and loved through these dark days, months and even years. Please do not battle this alone. Get help from others who have been in your shoes and can help you navigate dark waters so you don't drown.

You can also buy a copy of Shari Ann's novel "I See You" while you're there. This is the first in a series of books detailing the agony she endured thanks to childhood cancer.