

Inspiring Women



Fall Issue:
Women Who
Persist
- Part I -



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CELEBRATING LIVES ACROSS THE FAWCO WORLD

Saudi Arabia: Raising The Profile Of Osteosarcoma



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I have been a chemistry teacher and school administrator for over 20 years. I grew up in suburban Chicago, and after university settled back in the Chicago area with my husband, Eric. In 1999 we were so excited to have twins, Ian and Annika. After 13 years working in a fantastic suburban high school and when the twins turned eight years old, Eric and I decided to embark on a two year adventure to teach in an overseas school in Saudi Arabia. The expat life fit us so well that we made it more permanent, returning to Chicago for each summer but living and working in Saudi Arabia.

Three and a half years ago our lives changed forever when our 16-year-old son was diagnosed with an aggressive form of bone cancer called osteosarcoma. My son and I moved back to the States for his medical treatment, shuttling between Chicago and Saudi Arabia as his health allowed. Ian's diagnosis, combined with my step-mother's death from colon cancer about 15 years ago and my second step-mother's battle with breast cancer six years ago, compelled me to help those with cancer. I am currently involved in cancer activism in two main ways.

First, I volunteered to lead the AWEF's breast cancer heart pillow project. AWEF does a large fundraiser each year for breast cancer, and the money goes to making heart pillows that help breast cancer surgical patients keep their arms away from their surgical sites. The fundraising has been so successful that the group has allowed me to expand the project to also include childhood cancer patients this year. We hope that we can make IV pole lily pads for those children in hospital having chemotherapy.

My second form of activism is through the **MIB Family Agents**. MIB stands for Make It Better for children with osteosarcoma. In May 2016 MIB concluded that due to a lack of focus and funding,



when he was grieving and when fathers weren't traditionally single parents. He's always had a strong moral compass of right and wrong, while maintaining a great sense of adventure, optimism and humor. He has always been a steady, consistent source of courage and strength in my life.

I have met some of the most awesome people through my activism work. Truly, you can't find a more giving, compassionate and active set of people anywhere else. My activism work has also solidified what really matters in my life - family, friends and helping others. Many people are willing to be involved in activism but don't know how to begin. Opening that door of asking for volunteers and giving ideas of easy ways to get involved is often what hooks people into the cause. Activism is working to help others, but through giving of my time, energy and resources, I have been given so much more strength and peace.

I've been so surprised at how strengthening privacy in the medical field (a great idea) has dramatically effected the way people can get support. Although it is an unintended consequence of these measures, people have had to become more intentional and organized to get the support structures to people in need.



As a result of my efforts, in 2018 over 3.5 million dollars of research money has been given to osteosarcoma research specifically; just a few years ago there was almost no research money given to the disease specifically. The awareness of the disease is spreading, and funding is following. My son, in 2015, received the same chemotherapy regimen as Senator Edward (Ted) Kennedy did in 1973 and Canadian runner Terry Fox did in 1980. The disease prognosis and treatments haven't changed in over 40 years; finally, time and effort are being put into combatting this disease.

This is our world, our nations, our families and our people - we must work together to make it a better place for everyone. Find your niche and your passion - follow that and you will get back so much more than you give.

GETTING TO KNOW LIZ

What personal motto do you live by and how does it affect what you do/don't do? "Live with Purpose" is the motto I try to live by. I try to determine what is important in life and use that to guide my time and energy.

If you were stranded on a desert island, which would you rather have with you: The Bible, the complete works of Shakespeare or the history of civilization? Probably the history of civilization, as it is something that I find I know far too little about and the lessons that can be learned by prior people's choices can help to inform future thoughts and choices.

What one thing would you change about yourself if you magically could? My need for lots of sleep. I regularly need 8-9 hours of sleep, and I often envy my husband who only needs 5-6 hours. An extra few hours a day would be great!

What's your favorite indulgence? Travel, I absolutely love it. Seeing new places, wandering new streets, eating new food and talking to people are such a joy.



osteosarcoma research was stagnant and needed to be pushed forward. An initiative to hold the first and only annual osteosarcoma conference was brought forward, and I immediately volunteered to help. In January 2017 we held the first conference named FACTOR (Funding, Awareness, Collaboration, Trials, Osteosarcoma Research), and I was the patient advocate coordinator and the conference floor coordinator. FACTOR was

a huge success, bringing together over 100 doctors, patients, researchers and families to discuss the current state of osteosarcoma, while looking at and funding the most promising research. In January 2018, when the second conference was held, I began the planning for a "Family Agent" group, which would help families new to osteosarcoma or new to a relapse, find a patient and family to support them in their journey. Since then, I have worked on developing a book for osteosarcoma families to help them through this time, which will be available free of charge on the MIB website in late fall 2018, as well as a set of training modules for patients and families serving as Family Agents, available beginning in winter 2018/19. My son and I first met another osteosarcoma patient and family more than a year after his diagnosis – feeling alone during this period makes the journey through this horrible cancer so isolating and scary. Osteosarcoma requires some of the most brutal treatments: amputation, bones being replaced by feet of metal and brutal chemotherapy, followed by a life-long set of side effects from the attempt to cure the cancer... and too often the cancer cannot be cured.

My life has been impacted dramatically by cancer, and my one common experience through my mother's, my step-mother's and son's illnesses is the feeling of helplessness, isolation and fear. While I am not a cancer researcher to help change the prognosis or improve treatments, I do have the power to help others feel less hopeless, isolated and alone; and I also have the power to help bring researchers together, so they can put their brilliant minds together to help change the prognosis and treatments with the research dollars that I can help to raise. This work has helped me take power back when cancer stole my hope and power. It also helps me to memorialize my stepmother, who passed away from colon cancer in April 2005, and my son who passed away from treatment-induced leukemia in July 2018 from the chemotherapy treatments he received to treat his osteosarcoma.

My father has always been an amazing role model in my life and inspired my activism. He became a single parent of my brother and me when we were only 2 and 3 years old when my birth mom died. He worked hard to be positive and involved at a time

