



Pediatric Cancer Awareness Month: A Personal Story

September is always a busy month. The lazy days of summer begin to fade, and autumn approaches with its new beginnings: apples ripen, pumpkin-flavor explodes into everything, and for parents of school age kids, it heralds the start of a new school year.

September is also Pediatric Cancer Awareness month. For parents, siblings and friends with a connection to pediatric cancer, the new school year can be an especially tough time. It can be an abject reminder of the absence and the intangible presence of a loved one.

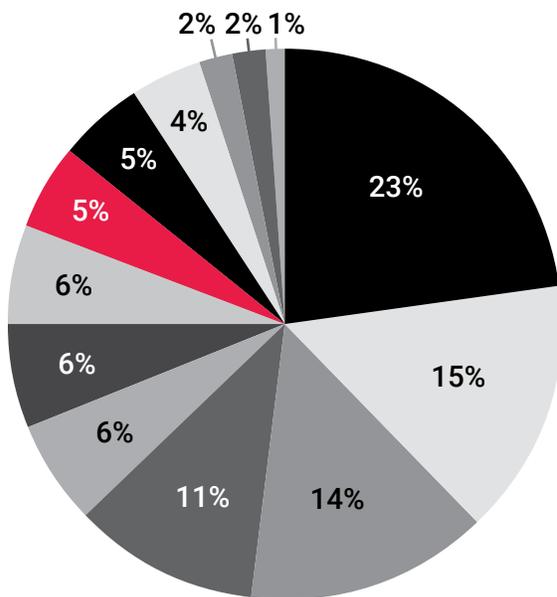
My family has a personal connection to pediatric cancer. We lost our daughter, Sydney, to complications from neuroblastoma a week before her 8th birthday. She would be starting 4th grade this month.

Neuroblastoma is a rare pediatric cancer that originates when nervous system stem cells don't turn off and, instead, grow and become malignant. Quite literally, she was born with cancer, and fought the disease three times.

I'm going to share some background on pediatric cancer that may be difficult for some to read. No one knows this better than my family, but it's important to understand how pediatric cancer patients around the world are being helped by new research that's improving prognoses and giving hope. My experience with pediatric cancer is very US centric. My intent is not to downplay or minimize the significance anywhere else, but rather to ground an emotional discussion based on my family's experience.

15,000 children in the US are diagnosed with cancer each year. One in ten will die. Pediatric cancer is the leading cause of disease-related death in US children¹, accounting for 44% of disease deaths in kids.

Pediatric cancer is unlike cancer in adults in nearly every aspect: medically, social-emotionally and outcome-wise. Children's and adults' bodies are fundamentally different. This may seem obvious, but it is medically significant. Different age groups have different hormones and even shared hormones are present at different levels. They're still growing, they heal rapidly and have energetic marrow. But, they are also undeveloped. Pediatric patients tend to recover from surgery much faster than adult patients, but because of less developed



- 23% Leukemia
- 15% Brain and Central Nervous Systems
- 14% Lymphoma & Reticuloendothelial Neoplasms
- 11% Epithelial Neoplasms & Melanomas
- 6% Rhabdomyosarcoma
- 6% Thyroid Carcinoma
- 6% Germ Cell Tumor
- 5% Neuroblastoma & Other Peripheral Nerve Cell Tumors
- 5% Bone Tumor
- 4% Kidney Tumors (including Wilms)
- 2% Liver Tumors (including Hepatoblastoma)
- 2% Retinoblastoma
- 1% Other

liver and kidney function, they can struggle with treatments that adults can handle. Kids are smaller than adults. Tools drug regimens and training are overwhelmingly focused on treating adult patients. For example, endoscopes—a tool used to view or biopsy material in a non-invasive manner—are designed for adults, not children. A pediatric endoscope is simply not a thing.

Family-centered care is at the core of treating children with cancer, rather than patient-centric care for adults. Pediatric oncology rooms, generally, come with a place for a parent to sleep. Take a child, and add debilitating treatment that requires near constant attention, planned and unplanned trips to the hospital, long stays and vigilance and you get the idea. Terms like, *Cancer Family* and *Cancer Parent* are common shorthand. Siblings have it especially tough, and are often referred to as, *Cancer Orphans*. Coughs, fevers and the flu are constant worries. One of the silver linings of Covid was that Facetime playdates were easy and common, giving immunocompromised kids the ability to socialize with peers and grasp moments of normalcy.

Most adult cancers, when treated successfully, go into remission. Many pediatric cancers are no longer just treatable, but curable. In the cancer world, “cure” is a strong word, used with care and precision. The child’s body, still growing and learning, has an opportunity to shift and change in ways that adult bodies do not. Neuroblastoma, for instance, is the only human cancer that can sometimes suddenly switch off. The stem cells receive the, *Shut down and stop growing!*, order and they behave like normal stem cells. Instances where a teenager or adult is in surgery after a car accident and a non-malignant neuroblastoma tumor (ganglioneuroma) is found are rare, but well documented.

The biggest challenge with pediatric cancer is that few institutions, and even fewer pharmaceutical companies, focus on new treatments specific to pediatric oncology. The hard truth is that there are too few patients for it to be financially viable. This means that treatments are often repurposed adult-oriented regimens and drug

classes. It also means that roughly 2/3rds of pediatric survivors develop a chronic health condition as adults due to toxic treatments². Biologics have begun making their way into pediatrics in the last few years and show tremendous promise as they make use of the body’s immune system. My daughter, for instance, did multiple cycles of Dinutuximab during her final course of treatment. It is a neuroblastoma-specific biologic that attacks types of nervous system stem cells. A recent ten-year study of the drug showed remarkable efficacy if used early, but the study took a decade to complete due to few patients and lack of funding.



Picture 1: Pan Mass Challenge Bridge of Hope to the Jimmy Fund

It is for that reason I am especially proud and humbled that UnitedLex’s Upward! Foundation continues their annual donation to support the Dana Farber Cancer Institute and The Jimmy Fund to fund pediatric cancer research, and specifically to support the Sydney Mirick Memorial Neuroblastoma Fund. The Jimmy Fund is a pediatric cancer focused institution pioneering novel, pediatric-centric cancer treatments. They develop and provide some of the best cancer care ever found. My family set up a fund through DFCI/ JFC to support neuroblastoma research and reduce the amount of time required



Picture 2: Recent Platelet Donation

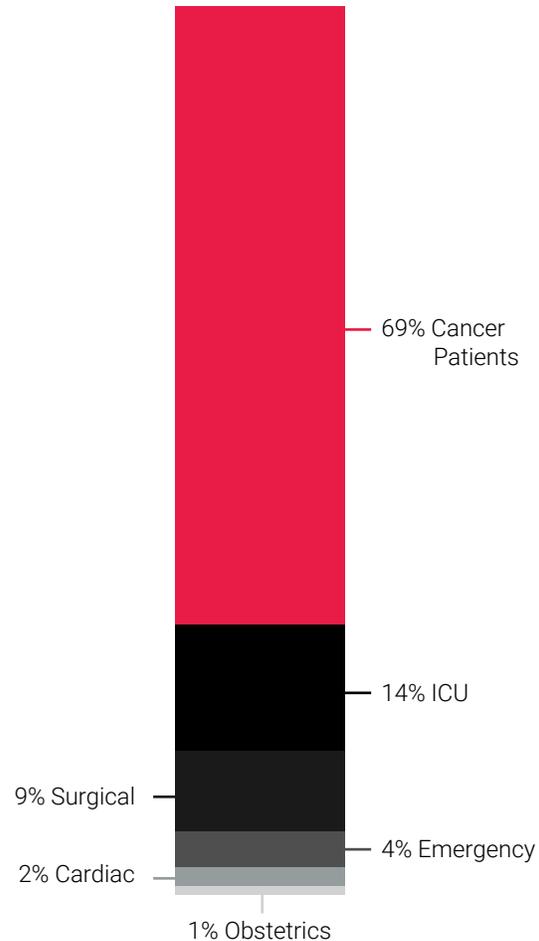
Platelets

Cancer treatments like chemotherapy target and kill rapidly dividing cells. Hair rapidly divides as it grows, which is why patients lose it. Patients also become immunocompromised, have low energy and look pale because blood is rapidly dividing. Red and white blood cell counts plummet. Platelets, the bit that lets you clot if you scrape your knee or cut yourself, precipitously drop. Even a young body, with robust marrow and growth hormones, can quickly become dangerously neutropenic. Recovery takes 8-12 days, post-treatment, even with marrow-supporting drug infusions. That's 8-12 days of low energy, of a pale, wan face, and of vigilance for cuts and scrapes. With a young child, or multiple kids, or kids and pets, the parental anxiety around inadvertent cuts and bumps increases. And if there is a cut or a major bruise it can mean rushing to the hospital for a platelet infusion, or potentially an in-patient stay.

Platelets literally save lives.

Platelet Challenge

Donating platelets is easy and always in need. Each donation yields between one and three units and most go to patients undergoing cancer treatments. Unlike red blood donations, which remain viable for weeks, platelets are only good for about seven days. And, unlike red blood donations where you might feel woozy or lightheaded after, platelet donations return your red blood, and you feel fine after—but you still get cookies and juice!



My wife and I donate at Dana Farber every few weeks. Our average is ~2.5 platelet units, each, per donation. We hope to reach 100 platelet units by the end of the year. We would love to challenge the UnitedLex community to match our platelet donations and collectively donate over 200 platelet transfusions to patients in need by the end of the 2022.

Donations can be done through the American Red Cross or any major hospital or health system. If you need help finding a location, please email me and I will happily assist. After you donate, ask your nurse to estimate the number of units donated and send me an email or a Teams chat. I will track and then report out by the end of the year!

Thank you all and thank you to the Upward! Foundation for their continued generosity and support of pediatric cancer research.

If you'd like to read more about Sydney, her treatment or the experience of treating pediatric cancer, we kept a CaringBridge going throughout. [Sydney | CaringBridge](#)



References

1. Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System, Mortality 1999-2020 on CDC WONDER Online Database, released in 2021

2. [Childhood Cancer Infographics | CureSearch](#)