

Winter 2019

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Cancer Fears Me

By Lacey Breeden- Cool Kid

Cancer feared me because the day I was diagnosed with stage two Hodgkin's lymphoma was the day I decided there was no way I was letting cancer control my life! Rather than being sad and asking, why me? I took the process of chemo, then radiation day by day. Each treatment was a step closer to beating this horrible disease.

I fought not only for me, but also for my family, who I knew could not stand to see me that way. Cancer taught me independence and I was the only one who could fight this battle for me. Doctors could give me all the drugs in the world, my friends and family could give me all the support in the world, but it was up to me to individually decide how badly I wanted to kick cancer to the curb.

Once cancer feared me in my mental state, there was no way it was getting me down. While being treated I tried my best to do everything a normal 17 year old would do. This included prom, graduation and going to the gym every chance, I was able

to. I never let cancer take control of my life- I controlled cancer. The day I was told I was in remission was easily the best day of my life. It was also the day where I felt the strongest mentally and physically. There is no longer any single thing that can stand in my way.

My advice to anyone struggling with this horrible disease is to control your own life rather than letting cancer control you. Shave your head rather than letting chemo take it away. Go on that walk outside, take those needles like a champion, and most importantly rather than fearing cancer, let cancer **FEAR YOU**.



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Check us out on social media:



SELF CARE

(excerpt from the book: "You Are Not Alone")

By Deanne Ford, Parent

After the first couple of months, I allowed myself to think about me, it took a while and I still struggle with that now sometimes. I am a caregiver and find joy when I can help ease someone's struggles, especially my family members.

But I have learned that something as simple as going home for a day from the hospital was good for me. I could let someone else volunteer to stay there while I went home, showered and even slept in my own bed. Once in a while I would allow myself to put on earphones and listen to music on my iPod and just close my eyes to escape for the moment.

I would get a pedicure once a month or so, a manicure less often than that, but just something for me. I found that journaling was very therapeutic for me, so the time I spend updating out Caring Bridge site was my time, sometimes, it felt like I was venting about cancer, about low ANC numbers, about whatever I wanted, it was a way to let go, and I got relief from doing it.

If someone asked while we were in inpatient if I wanted a coffee, a donut, a pack of gum, I would be grateful that someone wanted to give me something and I would accept. I would never turn down a gift card for the coffee shop in the hospital, since I was there so often, they would never go to waste, that's is for sure.

*To receive a free copy of
"You Are Not Alone",
please email
janet@coolkidscampaign.org
with your name and address.*



Thank You!

COOL KIDS I WORK WITH

By Morgan Garber, LMSW

I have been a social worker in Pediatric Oncology for several years now. It is such an incredible privilege to have the opportunity to be alongside these amazing kids and their families. For each family the priority is to get their child well but many of my families soon begin to vocalize other stressors that also affect them.

One of the largest and most common aspects for my families is the effect on schedules, and finances. This is why I love to provide my families with referral information to Cool Kids, A place where they can find community and moments to enjoy time together as a family.

Right from the start, Cool Kids sends out such a thoughtful care package to not only the child with the illness but their siblings as well. A great number of families have commented about the appreciation they have for these gifts. A sweet reminder that this disease effects the entire family. I have noticed that sometimes siblings can have a difficult time, as they have feelings of being ignored or not included during the treatment process. I am glad that Cool Kids can remind them that even if their days and family may look a little different, they are still vitally important and valued.

I also get the joy of watching inpatient families interact with Cool Kids through food and crafts once a month at the hospital. It has been fun to watch with several different families as a parent and child interact and create/design together, both with smiles and laughter. Afterwards it is not uncommon to enter their room and see their artwork decorating their walls or windowsill. The making of the monsters was one of my favorites!

I know that there is so much more that Cool Kids has been able to provide for my families, both that I have heard about and not heard about. I am so thankful to have such strong community resources that we can provide to our families as they navigate cancer and the challenging treatment process.

THANK YOU FROM MIA CROSS

By Logan and Reagan's Mom

My child's name is Logan Johnson and she is a twin with her sister Raegan. Logan was diagnosed with B-Cell Acute Lymphoblastic Leukemia in September 2016. Cool Kids Campaign is like a second family to us. Thank you for letting me feel safe when I drop off my kids for movie nights. I can have a "little" "me time" and my girls can enjoy lots of fun and popcorn. I also want to thank you for letting Logan & Raegan celebrate their 4th birthday party at the clubhouse. They love their Barbie dream house! Lastly, thank you to the great staff at Cool Kid's Campaign for your time & support helping families at their most devastating time.

Big hugs from the Johnson family!





Meet Dr. Jennifer Foster, the Researcher Searching for Cures for Rare Cancers

by Trish Adkins



For Eden, the trouble began when she was 10 years old. The trouble had a name: pain. It seemed normal at first—maybe a side effect from dancing or growing. But then it never went away and then, suddenly, Eden could not dance anymore.

“I knew in my heart it was more than growing pains,” said Eden’s mom, Shannon.

A MRI revealed the source of the pain: a tumor on her leg. And not just any tumor, it was a tumor so rare that it had never been seen before. They nicknamed it Eden’s Tumor. Eden’s doctor, Dr. Jennifer Foster at Texas Children’s Cancer Center turned to research to find a treatment plan for Eden. Eden went through treatment once and then her cancer returned, this time in her shoulder.

Eden is now enrolled in a clinical trial for children with relapsed tumors. We spoke with Dr. Foster about Eden’s tumor, her treatment and how innovative clinical trials are propelling the world closer to cures.

ALSF: What type of cancer does Eden have?

Dr. Jennifer Foster (JF): Eden has a tumor that has not been described before. Our team ended up calling it a “primitive round blue cell primitive neural tumor.” But, really, we just refer to it as Eden’s Tumor, since it is the only one of its kind anyone has ever described.

ALSF: Wow, walk me through what happens when a tumor like Eden’s lands on your desk?

JF: Until we can describe the tumor, we cannot treat it. This is true for both rare and less-rare tumors. We tapped into our large team of pathologists, solid tumor oncologists, radiologists and other childhood cancer experts across the country to come up with a description of the tumor.

ALSF: What are the features that make Eden’s tumor so rare?

JF: Eden’s tumor has several features that make it so unusual. First, the tumor did not pick up on an MIBG or bone scan, which are scans used to detect neuroblastoma cells. Yet, the pathologists could tell the tumor had some characteristics of neuroblastoma. The PET scan did pick up the tumor cells in Eden’s leg, shoulder and throughout her body.

Pathologists looked at samples of Eden’s tumor under the microscope and not only saw the neuroblastoma features, but also saw some features of the common bone cancer Ewing’s sarcoma. When we sequenced the tumor to study its biology, there were no genetic hits against a wide panel of known markers of cancer.

ALSF: So, how do you treat something that isn’t anything that has existed before?

JF: We heavily relied on the pathology report to create a treatment plan that we knew to be effective against both neuroblastoma and Ewing sarcoma. We chose chemotherapy drugs known to work on both cancers as well as radiation, which we know kills both of these types of cancer cells. The treatment was effective and the tumors responded. Unfortunately, Eden relapsed 1 year off of therapy, this time in her opposite shoulder.

ALSF: What happens when a child like Eden relapses?

JF: When any child relapses, we know that the standard of care did not work and we have to try something new. Often, tumors are harder to treat after relapse. So, we turn to clinical trials and research to find potential solutions. For Eden, the biopsy of her relapsed disease showed that the tumor looked exactly the same under the microscope as it did at diagnosis. Since the first round of treatment did not work, we had to come up with a new plan. For Eden, that plan was a new clinical trial opening both at Texas Children’s Cancer Center and at other select institutions across the country.

ALSF: What is the name of the trial Eden is on?

JF: The official title of the study Eden is a part of is “ADVL1615, A Phase 1 Study of Pevonedistat a NEDD8 Activating Enzyme (NAE) Inhibitor, in Combination with Temozolomide and Irinotecan in Pediatric Patients with Recurrent or Refractory Solid Tumors”

ALSF: How does the drug work?

JF: Pevonedistat is a novel agent that we use in combination with two standard chemotherapy regimens (Temozolomide and Irinotecan). Pevonedistat may work in combination with Irinotecan and temozolomide by blocking some of the enzymes needed for cell growth, thus stopping the growth of cancer cells.

The pre-clinical lab testing of this combination has shown great promise and this drug has also showed success in clinical trials for adults with cancer. As long as Eden is responding to treatment, she will have up to 17 cycles of therapy over about a year.

ALSF: Why are childhood cancer research and clinical trials so important?

JF: The trial Eden is on represents 10 years of process—pre-clinical experiments in the lab, adult clinical trials, and the building of the infrastructure necessary to support a clinical trial. We don’t have the full story for most types of childhood cancer. Continued research and clinical trials will help us learn the full story, so we can start making the drugs and agents that can cure future children diagnosed with cancer.

ALSF: How can studying a rare, one-of-a-kind tumor help other kids battling cancer?

JF: Every piece of knowledge we gain from rare tumors like ‘Eden’s tumor’ will build and help guide us in future treatment decisions for other children; just like how the knowledge has guided us to this point of being able to help Eden.



YOU CAN MAKE A DIFFERENCE for children, like Eden, who want more opportunities to receive potentially lifesaving treatments and hope for a brighter, healthier future.

YOUR GIFT will fund the most promising, innovative scientific projects with the likelihood of making an impact.

YOUR SUPPORT allows Alex’s Lemonade Stand Foundation to continue to fund researchers around the country to develop less-toxic treatments and more cures for kids with cancer. **DONATE**, today.

alexlemonade.org

PUZZLES AND GAMES

FIND THE HIDDEN PICTURES



In the big picture, find these objects.



apple



ladle



mushroom



spoon



ice-cream bar



candle



pencil



mallet



sock



fish



bell



fishhook



tack



mitten



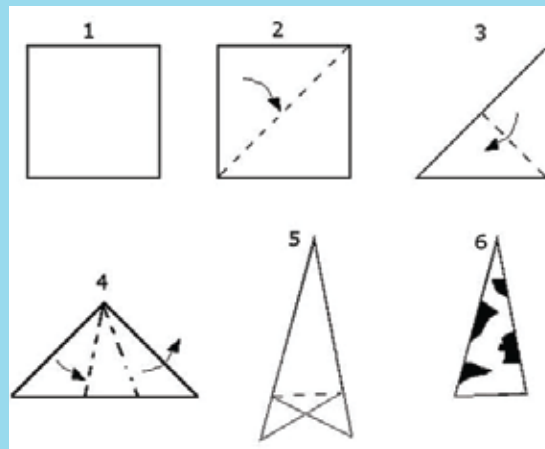
needle



baseball bat

CUT YOUR OWN SNOWFLAKE

1. Get a square piece of paper or trim a piece of paper so that it is square.
2. Fold your square in half diagonally (have a look at the picture below).
3. Fold your triangle in half – again diagonally (look at the picture below). Fold paper in thirds ... one side to the front, the other to the back.
4. Trim the extra piece of paper off the end of your small triangle.
5. Around the outside of your triangle, cut some fun designs — circles, squares, triangles, squiggles ... anything goes.
6. Unfold your paper and look at your masterpiece. Voila! A snowflake.



WINTER WORD SCRAMBLE

TBOOS _ _ _ _ _

OCAOC _ _ _ _ _

CLOD _ _ _ _ _

ATH _ _ _ _

LIICEC _ _ _ _ _

ITTNME _ _ _ _ _

CARFS _ _ _ _ _

SLHEVO _ _ _ _ _

KIS _ _ _ _

LDES _ _ _ _ _

WNSO _ _ _ _ _

NREWIT _ _ _ _ _

ANSWERS:
BOOTS, COCOA, COLD,
HAT, ICICLE, MITTEN,
SCARF, SHOVEL, SKI,
SLED, SNOW, WINTER

BRAIN TEASERS

SNOWMAN MAZE



Snow Day!

All Letters
 $3 + 2 =$

$4 + 1 =$
 $2 + 3 =$
 $8 + 2 =$
 $0 + 5 =$
 $5 + 3 =$
 $6 + 3 =$
 $6 + 1 =$
 $6 + 2 =$
 $7 + 1 =$
 $7 + 3 =$
 $4 + 5 =$
 $5 + 5 =$
 $4 + 6 =$
 $4 + 4 =$
 $1 + 5 =$
 $6 + 0 =$
 $9 + 1 =$
 $6 + 4 =$
 $3 + 5 =$
 $5 + 2 =$
 $4 + 3 =$

DIRECTIONS: Solve each addition problem. Then use the key below to color the picture.

KEY:
 5 = Yellow, 6 = Blue, 7 = Orange,
 8 = Pink, 9 = White, 10 = Black
 Any blank spaces color white.

See how many words can you make out of:
WINTER WONDERLAND



IT'S FUN **TO LEARN FACTS!**

ALL ABOUT PENGUINS

Penguins are birds that do not fly, but can swim 20 miles per hour.

Penguins eat fish, squid, krill, shrimp and other crustaceans. They catch their food in the water using their beaks and swallow it whole.

Penguins live mostly in Antarctica, South America, South Africa, New Zealand and Galapagos Islands. No penguins live in the North Pole!

The largest penguins are the emperor penguins. They can be 3 feet 7 inches tall and weigh 75 pounds. The smallest penguins are the little blue penguins also known as fairy penguins. They are only 16 inches tall and weigh 2 ½ pounds!

It takes about 35 days for a penguin egg to hatch. A baby penguin is called a chick and will leave the nest when they are around one month old.

Penguins can be playful. They like to go tobogganing. They will lay on their tummy and slide through the ice and snow. Penguins will also dive off cliffs into the water, get out and dive again for fun.

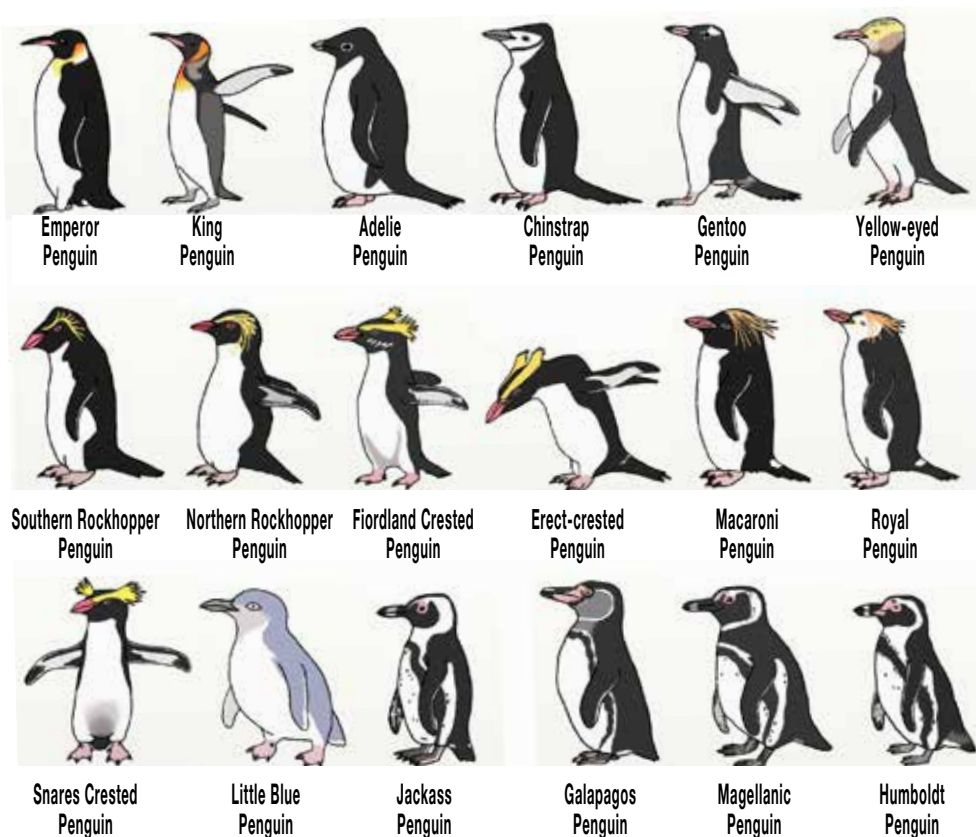
A group of penguins in the water is called a 'raft'. On land, they are called a 'waddle'. Other collective nouns for penguins include rookery, colony, and huddle.

PENGUIN WORD SEARCH

P	J	E	S	P	V	F	Y	O	D
O	R	A	J	K	C	A	L	B	T
D	I	V	E	O	N	S	F	F	O
N	A	Y	Z	O	D	U	V	K	L
I	D	R	I	B	L	A	L	A	L
U	A	V	I	D	O	U	E	F	I
G	E	G	G	I	C	F	T	P	R
N	D	I	M	U	H	S	I	F	K
E	Q	W	U	Q	O	Y	H	O	I
P	M	H	P	S	M	L	W	U	Y

Can you find the following words?

PENGUIN - COLD - SQUID - FISH - KRILL
 WHITE - BLACK - EGG - BIRD - DIVE



JOCKEYS RIDDLES

SNOWMAN FUNNIES



WINTER RIDDLES

Q: Why did the boy keep his trumpet out in the snow?

A: Because he liked cool music.

Q: What did the snowman have for breakfast?

A: Frosted Snowflakes

Q: What often falls in the winter but never gets hurt?

A: Snow

Q: How does a penguin build a house?

A: Igloos it together.

Q: What do you get when you cross a snowman with a vampire?

A: Frostbite.

Q: How did Jack Frost get to work?

A: By icicle.

Q: What's it called when a snowman has a temper tantrum?

A: A meltdown.

Q: What is a snowman's favorite snack?

A: Ice Krispy treats.

Q: How do you scare a snowman?

A: Pull out a hairdryer.

Q: How was the snow globe feeling after the scary story?

A: A little shaken.

I AM A MOMAGER

By -Melanie K.

Just about every morning this month, I have woken up suddenly, in the darkness of a still and quiet winter morning. My eyes pop open wide as if startled and a kind of chill runs through my body though I'm tucked securely underneath the warmth of my faux down comforter. The sound of my forced air heater gently humming in the background but the beat of my heart pounding loudly in my ears. I want to get up and escape the weighted pressure in the middle of my chest. I want to scream and yell out "let me go!" but I'm held down to the mattress by a force I cannot see but a tightness I can feel strongly overcoming me. I take my next breaths so deeply that I surprise myself at the volume of the exhale and feel the frustration of being held down by the hands of anxiety.

I AM A MOMAGER AND I DO NOT HAVE TIME FOR THIS HEAVY ONSLAUGHT OF EMOTIONS.

On this particular morning, my mind would not let me go as I thought through the events and timing of the day. What I needed to pack for the hospital - food, water, blanket, iPad, headphones, a book, the medicine list, phone charger, my laptop, the pre-paid parking garage stickers, hand sanitizer and the Lego figurines - check. I fluttered through my mental "to do before leaving home" list - stop thinking and pray, turn on my out-of-office message, get Noah's clothes out of the dryer, turn on the dish washer, make a smoothie, send my husband his "honey do list", check my work and personal email, call my mom, tell my daughter to clean her room...again (LOL), confirm the dentist appointments, put that stack of papers into the recycling bin, grab the grocery list and put the Lidocaine cream on Noah's chest so that the skin covering his port is numb for the needle stick - check.

I AM A MOMAGER. I HAVE A CHECK LIST FOR MY CHECK LISTS AND I DO NOT HAVE TIME TO BE HELD DOWN WHEN THERE IS SO MUCH TO DO.

My mind flashed back over the medicine and supplements I reorganized the night before at home - Dexamethasone, Mercaptopurine, Sulfamethazine, Methotrexate, Senokot, Docusate Sodium, Oxycodone, Polyethylene Glycol, Ranitidine, Lidocaine and Zofran. I cut pills in half and verify we have enough to get my son through the next month. I cycle through my brain what day and time he needs to take each pill. I know the dosage, shape, color and, yes, the smell of each one. I know which pill is for nausea, which for pain and which for constipation. I know which one upsets his stomach, which one makes him dehydrated and which one makes him grumpy. We have a Family Rule - no one in my house is allowed to talk to me when I'm filling up the weekly medicine box! Period.

I AM A MOMAGER AND I'M FOCUSED. I'M ON IT. I'VE GOT THIS!
(YEAH, I'M TRYING TO CONVINCE MYSELF)!

I look at the time and map out which route I will take. I know the three main ways to get to the Hospital and how long each will take depending on what time of day it is. I know which lane to drive in to get through the traffic the quickest. I know which level of the parking garage always has a spot and where never to go. I know which elevator runs the smoothest, which bridge gets me closest to the children's hospital entrance and which security guard will get me my badge the fastest. I know how to navigate through the 1st, 2nd 4th, 10th, 11th and 12th floors with ease, the best and worst times to get to the cafeteria and the exact cost of our regular order in the café. I know where it's noisy and where it's quiet and the name of most nurses in the pediatric oncology outpatient clinic. Most importantly, I know where the cleanest bathrooms are located and which clinic rooms my son prefers because he's been treated in every single one of them.

I'M A MOMAGER AND I KNOW STUFF.

We were headed back to the hospital as we have every week for over a month because his white blood cells took an enormous dip in the wrong direction and hadn't recovered, making him very vulnerable to illness. We sat on pins and needles the first week as his temperature hovered at around 99.7 and a reading 100.4 would mean an admission to the hospital. Can you feel my anxiousness? The effects of "Chemo Brain" and bouts of fatigue were causing him to space out and fall asleep in the class room. Within a matter of days, he was taken off several of his chemotherapy meds, pulled out of school for at least the next 2-4 months and back to wearing a mask for a while, mostly in crowds. Since this is one of his least favorite things to do you can imagine how well it went over with my 9-year-old. It feels like we are going backwards rather than forward. And low counts are scary...that's how this whole cancer journey got started in the first place.

BUT I AM A MOMAGER!

I've planned and re-planned the schedule, my work life, the babysitters, the at home teacher, the doctors' appointments and now my son's counseling for his fears and anxiety. I can handle this redirection like a champ! After all, I've already been doing it for three years with my God, my husband, my daughter, my mom and our tribe of Aunties, Uncles and Friends. I am the same Momager that has managed a demanding full-time job during the worst time in my life, kept a binder for my son's illness and another for all the medical bills, watched about twenty food and health documentaries, read articles and books, managed our meal plans as we changed to a mostly plant-based diet and replaced almost every product in our home with a natural one. You name it, I've tried to juggle it all.

I AM A MOMAGER AND WE ARE GOING TO LIVE BY GOLLY - EVEN WITH CANCER.

So whenever possible and my son is feeling good - movies, vacation, swim lessons, piano lessons, drum lessons, school, summer camp, church, flag football, time for friends, volunteering to help others with cancer, support organizations that help critically ill children and sleeping in on Saturdays. We let our son be the rock star that he naturally is whenever possible! We are not going to waste our suffering. We are not going to waste our lives. We just keep going and living because this is all we've got!

I'M A MOMAGER! A VERY TIRED, WORN DOWN MOMAGER.

I've been Momaging everyone and everything but myself. I need to take care of my son and get him through this time. I need to learn to be a better mom to my daughter and a better daughter to my mom. I need to nurture my marriage, restore my relationship with my God, take care of my home and hold on to my family and friends. I can't do it all and I don't want to. I need sleep. I need to surrender and rid myself of this stress like all the old clothes I can't fit in my closet.

I NEED TO MANAGE ME.

COOL KIDS WE L♥VE

*Send us your stuff and become a
published writer or artist!*

*Send us your stories, art, poetry,
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want to see in print!*

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Towson, MD 21204.*



CORA



EVY



BRIXTON

Children are at the heart of our care

From pediatric medicine to specialty care,
the Herman & Walter Samuelson
Children's Hospital at Sinai offers exceptional
care and support for children and their families.
lifebridgehealth.org/childrenshospital



The Herman & Walter Samuelson
Children's
HOSPITAL AT SINAI



Cool Kids CAMPAIGN®

Learn About Our Club House



Cami, Relapsed Acute Lymphoblastic Leukemia

**Helping kids with pediatric cancer and their families
is what Cool Kids Campaign is all about.**

In our Learning Center, we focus on the academic, social and emotional needs of children living with cancer.

Our programs include one on one tutoring, Mommy & Me for the little ones with cancer, Super Sibs to focus on the issues of the siblings and a Teen Club for patients and survivors.

All Cool Kids Campaign programs are free to families and children living with (or survivors of) pediatric cancer.

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CHEMO CAPS ONLY \$6 A PIECE!



**CANCER
FEARS** *Me*®

*is a strong, positive mindset for those living with cancer,
their support groups and caregivers.*



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QUANTITY/COLORS - write quantity in box: ☐ Navy ☐ Raspberry ☐ Surfer Blue TOTAL DUE: _____

PAYMENT - Checks made out to 'Cool Kids Campaign' are preferred

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