Last time I wrote an article for Cool Kids, I was in remission. I was finishing up a year of treatment, I was getting ready to graduate with my class, and I was very excited to head off to Carnegie Mellon in the fall. So when something was found on my routine scans last July, I didn’t have to think twice about what it could mean. I had already achieved so much in the last 18 months, but in essence I was right back where I had started 18 months ago. So it left me with a new challenge: what could I do this time, that I hadn’t done last time, that would keep me cancer-free?

The way I look at things, I should focus only on the things that I can control, and commit all my strength and willpower to them. So I thought: “What exactly do I control?” I can try to live a healthy lifestyle, which means I should focus my efforts on eating right, exercising and being happy. The body goes through tremendous stress during chemotherapy, it requires more calories and nutrients than an average person does. I know it’s hard to get food in during chemotherapy, so it’s important to make the food count. I started juicing vegetables, which releases more vitamins versus cooking, and making fruit smoothies. Smoothies and juice are much easier to sip and get down compared to solid food, also. Exercise is not only good for your body, but it’s a lot of fun; In my opinion, nothing beats a good game of football with your friends. Also, keeping a stress-free lifestyle is very important to me, Being happy is, itself, a boost for your immune system. I’m taking two challenging classes at Loyola that are a lot of fun. By succeeding in class at Loyola, it has made me a lot more confident about going to Carnegie Mellon next fall.

Going there cancer-free, and staying that way is the ultimate goal. And I’m never going to forget that.

Check out Mike’s music at http://grenaders.info
**Ben**

- I felt really scared and I didn't want to stay in the hospital that long. I would miss my family and my friends. I didn't know what was going to happen next.
- I felt very scared and I didn't want to stay in the hospital that long. I would miss my family and my friends. I didn't know what was going to happen next.
- I was just a baby so I didn't know anything.

**Eddie**

- I didn't know what was going on so I just laid there, they wouldn't let me move. I went along with everything. I remember my coach brought me Taco Bell.
- I didn't know what it was really like to go through a cancer journey unless you have walked in those shoes. It is a unique situation for each child and their family, yet we hope that hearing what other kids have gone through will help you know what to expect and find it comforting that others have gone through it.

We pulled together five Cool Kids and their moms for a roundtable discussion about their experience with cancer. All five of these Cool Kids are now done with their cancer treatments and have successfully moved on with their lives. However, they still carry with them the memories of that challenging time in their life. Some of those memories aren't great but all of them agree that they learned a lot about themselves and others and even have some positive memories.

**How did you feel when you were first diagnosed with cancer?**

**Ben**

- I felt really scared and I didn't want to stay at the hospital that long. I would miss my family and my friends. I didn't know what was going to happen next.
- I was just a baby so I didn't know anything.

**Billy**

- I was really scared and I didn't know anyone and I was just really scared.
- I was just a baby so I didn't know anything.

**Molly**

- It is what it is. Enjoy life to the fullest.
- It will be alright, just think good thoughts. If you want to get better then you have to think you will.
- You can't give up hope, that's one thing you need. Make friends. Smile and try to have a good time. Find time to laugh and have a good time. Meet your nurses and doctors.
- Matt- Think positive because thoughts is going to be okay.
- Eddie- It is what it is. Enjoy life to the fullest.

**Kyralle**

- It will be alright, just think good thoughts. If you want to get better then you have to think you will.
- Ben- You can't give up hope, that's one thing you need. Make friends. Smile and try to have a good time.

**Kyralee**

- Eddie- It is what it is. Enjoy life to the fullest.
- Ben- You can't give up hope, that's one thing you need. Make friends. Smile and try to have a good time. Find time to laugh and have a good time. Meet your nurses and doctors.
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- It will be alright, just think good thoughts. If you want to get better then you have to think you will.
- Ben- You can't give up hope, that's one thing you need. Make friends. Smile and try to have a good time. Find time to laugh and have a good time. Meet your nurses and doctors.
- Matt- Think positive because thoughts is going to be okay.

**What was the worst thing (or bad memory) about having cancer?**

**Eddie**

- Oh, the needles. Two needles right into your legs for chemo and Lovencres to get rid of the clots. I got $100 from my grandmother for my last autologousg (chemo-drug).
- Ben- Buttrum, I had to take it three days a week and it was horrible. I missed all my friends from home and I didn't get to see my sister and dad much because I was always in the hospital bed.
- Kyralle- Probably just the medications.
- Kyralle’s mom, Resalee- It changed her in every way, once a month and made her really depressed. She was pale, depressed and would just stare out the windows.
- Matt- I was told I didn't like the needles.
- Billy- The thing I probably hated the most was missing my family and I tried a lot because I wanted to go home.
- Matt- I was told I didn't like the needles.
- Billy- The thing I probably hated the most was missing my family and I tried a lot because I wanted to go home.

**What was the best thing you did to keep your mind off of treatment?**

**Ben**

- The cruise from Make A Wish to Western Village. Also meeting all the nurses and doctors at the hospital.
- Probably just the medication.
- Fixing a lot of fun events.
- Fixing a lot of fun events.

**Billy**

- Fixing a lot of fun events.
- Fixing a lot of fun events.
- Went to the playroom, just do anything.
- Go to the playroom, just do anything.

**Kyralee**

- Fixing a lot of fun events.
- Fixing a lot of fun events.
- Fixing a lot of fun events.
- Fixing a lot of fun events.

**Kyralle**

- Fixing a lot of fun events.
- Fixing a lot of fun events.
- Fixing a lot of fun events.
- Fixing a lot of fun events.
How spoiled were you? (This question the moms throw in at the last minute…)

Ben - Not spoiled at all (he says sarcastically). All I had to say was "After all I’ve been through?"

Eddie - I used the peppers on the face.

Ben - I asked for chicken nuggets so my dad brought me some from Burger King but they had too much pepper on them. So, my dad went back out to McDonald’s to get more.

Billy’s Mom, Kim - Billy got shrimp and crab legs.

Kyralee’s Mom, Resalee - Well her father said she had cancer during her “developing years” so since everything was done for her during those 5 years she got lazy.

What did your friends do to help you?

Eddie - My class at school had a hat day. Kids in my class could donate 25 cents to wear a hat. Once my class could donate 25 cents to wear a hat.

Ben - My school taped the first day Billy’s Mom, Kim - These kids don’t let cancer define them. They are kids, they are people, they have lives. Every day there is something good. Ben’s Mom, Sue – They have joy in their lives.

Billy’s Mom, Kim - My friend brought a bag of cookie dough from her dad and lots of dirt cookies. So, my dad went back out to McDonald’s to get more.

Eddie - Maybe raised $500.00 and donated it to John Hopkins for Pediatric Cancer Research in 2009 in memory of Graham Harrison, a friend from the hospital and Camp Sunshine. He hopes to raise $500.00 again this year. He recycles empty ink cartridges donated by his school, a doctor’s office and the company his mother works for. The idea was presented on the John Hopkins TV show from another childhood cancer survivor. Eddie thought it was a unique idea to raise money.

Kyralee’s Mom, Resalee - One of Kyralee’s brothers is an art teacher, painted it. One of Kyralee’s sisters is to always be asked how is your brother/ sister?

How do you feel now?

Ben - I feel thankful that I made it through, I feel stronger. I am very thankful for the doctors for helping me. I try to help Cool Kids when they ask me to do something. I helped John Hopkins make a video about Sarcoma. We (my family) makes “friends” and angels for kids who we hear about who are in treatment. My sister, Olivia, has yard sales every year to raise money for different things, like sarcoma research.

Kyralee’s Mom, Resalee - When Dr. Wiley started seeing patients in the Bel Air office we check to see if more things are needed for the chest. She needed something from the chest but she wanted especially the younger kids to still have a prize. They have one at the ped’s oncology clinic in Sinai and it means a lot to the kids to have something to look forward to. So she asked if we could get a treasure chest for the new office. I bought the chest at Michael’s and Kyralee and a family friend, who was an art teacher, painted it. One of Kyralee’s father’s co-workers heard about what she was doing and made a request to the members of his church for items to fill it. Every time Kyralee has a check-up in the office we check to see if more things are needed for the chest.

Eddie’s Mom, Ladonna - Eddie raised $500.00 and made a request to the members of his church for items to fill it. Every time Kyralee has a check-up in the office we check to see if more things are needed for the chest.

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Is there anything you want to add or tell the kids who are currently going through their treatments?

Ben - I try to help kids who are going through treatment by giving them advice and letting them know that if it didn’t, it can too. I try to help Cool Kids when they ask me to do something. I helped John Hopkins make a video about Sarcoma. We (my family) makes “friends” and angels for kids who we hear about who are in treatment. My sister, Olivia, has yard sales every year to raise money for different things, like sarcoma research.

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We have noticed that once kids get through their cancer treatments they do like to help others who are going through it. Is there any special way that you have done that?

Ben - I try to help kids who are going through treatment by giving them advice and letting them know that if it didn’t, it can too. I try to help Cool Kids when they ask me to do something. I helped John Hopkins make a video about Sarcoma. We (my family) makes “friends” and angels for kids who we hear about who are in treatment. My sister, Olivia, has yard sales every year to raise money for different things, like sarcoma research.

Kyralee’s Mom, Resalee - When Dr. Wiley started seeing patients in the Bel Air office Kyralee was upset to find out that there was no treasure chest for the kids to pick a prize from after the visit. She was older then so Kyralee wasn’t really thinking that she needed something from the chest but she wanted especially the younger kids to still have a prize. They have one at the ped’s oncology clinic in Sinai and it means a lot to the kids to have something to look forward to. So she asked if we could get a treasure chest for the new office. I bought the chest at Michael’s and Kyralee and a family friend, who was an art teacher, painted it. One of Kyralee’s father’s co-workers heard about what she was doing and made a request to the members of his church for items to fill it. Every time Kyralee has a check-up in the office we check to see if more things are needed for the chest.

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Is there anything you want to add or tell the kids who are currently going through their treatments?

Ben – Don’t give up hope. Billy’s Mom, Kim – These kids don’t let cancer define them. They are kids, they are people, they have lives. Every day there is something good. Ben’s Mom, Sue – They have joy in their lives. Cancer is awful, but you have to keep your faith strong and your sense of humor intact. Make a point to laugh every day and make the most of each situation. Find the blessing in each day because no matter how bad it gets the blessings always outweigh the bad moments.

Eddie – Peace out!
**Happy Holidays!**

---

**WINTER WORD SEARCH**

- blizzard
- boots
- cold
- December
- earmuffs
- February
- freezing
- frigid
- frost
- icicle
- icy
- jacket
- January
- mittens
- plow
- scarf
- shovel
- skis
- sled
- slippery
- snow
- snowball
- snowboard
- snowflakes
- snowman
- windy
- winter

---

**Let It Snow**

Read the clues and fill in the blanks using the words in the box below.

1. Icy Cold
2. North Pole Animal
3. You wear them on your feet
4. It comes from the sky in winter
5. How you feel in front of a fireplace
6. Wear it around your neck to keep warm
7. A season

---

**Snow Boots Reindeer Warm Scarf Frosty Winter**
That's a Big Camera... By TJ Root

That’s a big camera,” I often hear muttered by astounded passersby. I crack an awkward smile. How should I respond? They’re not wrong. I’m usually using a big camera, but I can’t help but feel that they are doing more than simply commenting on the size of my camera. When someone strikes up conversation about how big my camera is, most of the time the next question is one of the following: is that yours, how much zoom does that thing have, who do you shoot for, are you a professional, and occasionally, how much does that thing cost? While each question has its own answer (yes, it’s mine; 300mm or 400mm or sometimes just “a lot”; my school paper; no, I’m a student; a lot), I never answer untruthfully, but I will admit that I can be a bit sarcastic at times; the answers are true, but they rarely tell the entire story. The last question is my favorite to answer. I never give out a figure because it’s not important. I’m not sure what they are looking for in my answer, but they often get an explanation: “I had lymphoma, and I actually got this lens, this camera, and this other lens (pointing to the referenced piece of gear each time) from the Make a Wish Foundation.”

They usually forget about the camera, sometimes giving me a look of puzzlement or disbelief. I think my full head of hair throws them. Some make note of my use of ‘had’ instead of ‘have,’ but all ask how I am doing. I respond, “very well, thank you. I had clean scans x number of months ago” (pausing to figure out when they last were). The next question is often how long ago this was. Every time I answer I have to pause and count it out. One would imagine that I would know in an instant how long ago I finished chemotherapy, but for whatever reason I only think about it when someone asks. People almost always say how glad they are to hear that I’m “doing better.” I politely say thank you and resume photographing. I smile and move on, because this is the most I ever think about my illness. In the eyes of the unassuming questioner, I just went from potentially spoiled kid with huge camera to cancer kid. The fact that I had cancer does not define me; I do not want the label of cancer kid. At that moment I am just a photographer. I tell my story not to elicit pity or to be identified as a cancer kid. Sometimes, I am embarrassed about how nice my gear is, but most of the time I am proud and grateful that I found an intense new passion for photography through cancer.

Editor’s Note: TJ is currently 17 and a senior at a private school outside of Baltimore. He was treated at Sinai Hospital and now works at a tennis club in addition to doing some freelance work for a newspaper as well as his school paper where he is the senior photo editor.

Share your thoughts, feelings, fears, experiences, and happiness. Our goal is to connect the pediatric oncology patients throughout the nation with each other. The Cool Kids Connection is published 4 times a year and sent to the hospitals. It is by you, for you, and about you! And we need YOU to make it happen. We are looking for articles, stories, poetry, drawings, photographs, puzzles, jokes, questions...anything you would like to share.

Please send your submissions by mail to: Cool Kids Campaign 9711 Monroe Street Cockeysville, MD 21030 or email to sharon@coolkidscampaign.org

Please include all of your contact information and a photo of yourself if possible. Please send only original art - we cannot use any copyrighted material.

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By his mom, Kelly Childress

It was the early August of 2009 when we noticed Elric’s behavior becoming increasingly worse. Elric has always been my laid back child, so temper tantrums and outbursts were not like him. We thought it was just him getting nervous about starting second grade.

Well he started school and when we got home that first day, he told me he didn’t want to go back because he had fallen getting off the school bus that morning. We tried to tell him it was okay, no one would make fun of him, he had to go to school. For about a week he would have massive temper tantrums about going to school, but once there he would calm down and go about his day.

The school nurse called one day and told us that Elric’s eye was “migrating” to the side and he was walking awkwardly. So off to his pediatrician we went.

His doctor took one look at him (mid-temper tantrum) and said that this wasn’t the child she has been taking care of since he was a baby.

About mid-September Elric had his MRI. A week later my husband Eric and I scoured websites trying to learn something about DIPG, what we found didn’t give us much hope.

On Elric’s 8th birthday everything quickly went downhill. He gained the weakness on his right side, so walking was not even an option at this point. His oncologist at CHKD (Dr. Pegram) did a CAT Scan and found that Elric had major swelling of his brain and massive fluid build up. So January 17, 2010 we headed back to St. Jude for a VP Shunt surgery.

In the process we found out that what we thought was his tumor growing and pressing on the spinal nerves causing the weakness, was actually a necrotic cyst in the middle of his tumor. He had his shunt placed and a few days later we noticed his abdominal incision leakage.

His doctors did a test to find out that the leakage was spinal fluid. So back into the hospital we went, they extracted his shunt tube from his abdomen, and check the spinal fluid drainage. That went well, so they kept him over the weekend and as his cyst drainage surgery was scheduled that Monday.

We finally got his shunt fixed and the cyst drained. We got through that with flying colors!

We returned to the Ronald McDonald House in Memphis where we were staying while at St. Jude’s.

As we were looking at being able to head home, Elric ended up unipotent again with an Upper GI Test, and a yeast infection growing in his abdominal incision. We spent 16 days inpatient having those taken care of.

A Wound Vac and MRI later, here it was March 2010. The MRI results stated that his cancer had spread to the tip of the left brain ventricle. He was taken off his protocol and put on a different chemo. It didn’t seem to help his tumor much.

In April Elric “lost” his voice for a day, so the doctors at St. Jude did a cat scan to find out what was causing it. What they found was a small brain bleed caused by a medicine he was on for a blood clot he developed in his leg from not being able to use his right side. We stopped the medicine and they placed a filter in the vein. Elric was able to talk again the next day, but his doctors wanted to do another MRI because his “cancer spread” didn’t show up on the CAT Scan.

On June 2nd we had been in Memphis for six months. The kids were getting worked up and wanting to go home, but we couldn’t until we had Elric back on track. We had another MRI and a side scan to find out that the “spread” wasn’t his cancer spreading, but fat cells from the high dosage of steroids he was on in January. We were elated! We only had the one tumor to deal with, and while it can take his life, we had positive results on his original protocol! The only downside was that his tumor had grown a bit causing more pressure on those nerves and therefore more weakness on his right side.

After about a month, we finally got Elric placed back on his protocol meds!

On August 2nd, almost eight months after we returned to St. Jude’s, we had another MRI and the results were fantastic! His tumor was closing in on itself from the cyst drainage, and the bits that grew were shrinking! We finally were told we could go home! Both the kids were so happy!

In September when we returned home, Elric improved daily. He had to learn to talk and walk again, and he is still working on walking. As of now, November, he’s doing a lot better. We’ve been back to St. Jude for an eight week MRI. As of that MRI we have almost 50% shrinkage of his Tumor.

He’s working hard in OT/P and regaining his strength, he is also getting a gait trainer to help “teach” him to walk on his own again! We are very excited! He’s doing well with his homebound school and loves his teacher Mrs. Whitmore. Other than that, he’s working on his strength on his right side and is enjoying sleeping in his own bed again.

We know we have a long road ahead of us, and we always have kids that live and have lived with DIPG for years and are doing well. Eric and I live with the thought in the back of our minds that we could lose Elric, but we don’t live like it! We take every day as it comes and help Elric to achieve his goals!

I myself have to say, I’m so proud of my son, he has taught me so much, and he is and will always be my hero!
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Doctor, Doctor Jokes

Doctor, Doctor I think I need glasses.
You certainly do Sir, this is a fish and chip shop!

Doctor, Doctor my son has swallowed my pen, what should I do?
Use a pencil till I get there.

Doctor, Doctor I think I’m a bell.
So why did you come around then?
Well, I saw this light at the window...!

Doctor, Doctor I think I’m a moth.
Who said that?

Doctor, Doctor I keep thinking I’m invisible.
Dreaming, after all, is a form of planning.

- Gloria Steinem
The family and friends of Derek Lloyd might call him “grumpy boy” but they know he sure is one smart cookie! Who else would ask for a boat to get off a deserted island? Say kids would get whatever they want. If you were the President of Whoville what would be your first act as the ruler? Say kids: “Say kids.”

What is your name? Derek Lloyd
Where do you live? Abingdon, MD
What grade are you in? Second
How old are you??: 12
What is your favorite subject in school? Math
If you were going to write a book what would it be about? Frogs & parrots.
What is your favorite food? Salt & vinegar chips and crab legs.
Do you have a BFF? Yes, Jarrett!

If you were one of the seven dwarfs, which one would you be? Why? Grumpy, cuz he’s upset. This helps not only the child, but their parents as well. It also makes it easier for the nurses and doctors to do what they need to do when the patients are calm and able to cooperate.

Where do you live? I live in Folsom, California which is a suburb of Sacramento- the state capital.
What is your name? Cammie Woodward
What time does your normal day start? Sometimes very early because I have a young baby, but usually I’m up around 5:30 a.m. to feed the baby and then start getting myself ready for work.
What is your favorite sport to watch? Ice skating.

What is your favorite kind of food? I love steak and potatoes! Hamburgers and sweet potato fries are my next favorite meal.
Favorite dessert? Candied yams have to be my favorite.
Favorite movie? Green Eggs & Ham
Favorite television show? Despicable Me
Favorite video game? Madden 11
Favorite sport? Football
Favorite kind of music do you listen to? All of it.

What is your favorite cereal? Cinnamon toast crunch
What is your favorite vegetable or fruit? Oranges
If you were stranded on a deserted island, what three things would you like to have? A house, a dog & a boat to get off of it.
What are you most grateful for? You can name more than one thing… My Mommy & Dad the mostest… all my family too- my brothers, my Mom-mom, my Mom-mom’s blue car & my Aunt Lisa and John. Plus I can go to school with my friends again!!!
What is your favorite book? Captain Underpants
If you were one of the seven dwarfs, which one would you be? Why? Grumpy, cuz he’s most like me.

What is your favorite thing about your job? The hardest part of my job is dealing with patients whose treatment has failed. I provide end of life support to those patients and their families, and while it’s very rewarding, it’s also very emotionally taxing.

What type of things do you like to do for exercise? Running, ride my bike & play football with my brothers.

If you were the President of Whoville what would be your first act as the ruler? Say kids.

What is your favorite subject in school? Math
If you were going to write a book what would it be about? Frogs & parrots.
What is your favorite food? Salt & vinegar chips and crab legs.
Do you have a BFF? Yes, Jarrett!

What do you like about dogs, cats, earthworms, birds?

To play? Skiing and snowboarding. I’m not that good, but I sure enjoy them!
Do you have children of your own? Yes, I have two boys. Zachary just turned 3, and Mason is 6-months old.

What do you like to do for fun? I love spending time with my family, and we love doing outdoor activities together, such as camping, hiking, and boating. I love to travel and explore new places. Photography is a passion of mine, so I always try to get great pictures wherever we go. I also love to scrapbook, but being a busy Mom, I haven’t found time to do that in a very long time.

What is your favorite movie? There’s so many I love, but one of my long-time favorites is Grease.
What was your favorite subject growing up? Besides recess I loved English and writing the best.
Favorite cereal? Lucky Charms
Favorite dessert? Crème Brûlée
Favorite kind of food? I love steak and potatoes! Hamburgers and sweet potato fries are my next favorite meal.
Favorite board game? Blokus, and I’ve taught it to our staff and patients, so we have lots of great games going sometimes!
Favorite card game? I’ve always enjoyed Uno.
What is your favorite food during the Thanksgiving celebration? I love it all, but I think that the candied yams have to be my favorite.

What do you have any brothers or sisters, if so- what are their names? My Mommy & my Aunt Lisa and John. Plus I can go to school with my friends again!!!

Do you have any brothers or sisters, if so- what are their names? (12), Darrius (9) & Nealen (4)

Where is your favorite place to be? At home with my brothers.

What do you like to do for fun? I love spending time with my family, and we love doing outdoor activities together, such as camping, hiking, and boating. I love to travel and explore new places. Photography is a passion of mine, so I always try to get great pictures wherever we go. I also love to scrapbook, but being a busy Mom, I haven’t found time to do that in a very long time.

What is your favorite movie? There’s so many I love, but one of my long-time favorites is Grease.
What was your favorite subject growing up? Besides recess I loved English and writing the best.
Favorite cereal? Lucky Charms
Favorite dessert? Crème Brûlée
Favorite kind of food? I love steak and potatoes! Hamburgers and sweet potato fries are my next favorite meal.
Favorite board game? Blokus, and I’ve taught it to our staff and patients, so we have lots of great games going sometimes!
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Do you have any brothers or sisters, if so- what are their names? My Mommy & my Aunt Lisa and John. Plus I can go to school with my friends again!!!

What is your favorite subject in school? Math
If you were going to write a book what would it be about? Frogs & parrots.
What is your favorite food? Salt & vinegar chips and crab legs.
Do you have a BFF? Yes, Jarrett!

What do you like about dogs, cats, earthworms, birds?

To play? Skiing and snowboarding. I’m not that good, but I sure enjoy them!
Do you have children of your own? Yes, I have two boys. Zachary just turned 3, and Mason is 6-months old.

What do you like to do for fun? I love spending time with my family, and we love doing outdoor activities together, such as camping, hiking, and boating. I love to travel and explore new places. Photography is a passion of mine, so I always try to get great pictures wherever we go. I also love to scrapbook, but being a busy Mom, I haven’t found time to do that in a very long time.

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Welcome to Cancer Fears Me - a strong, positive mindset for those living with cancer, their support groups and caregivers.

We know fear is a dominant emotion when someone is given a diagnosis of cancer. Cancer Fears Me turns that fear around and puts you in control.

Cancer Fears Me was born after years of working with families living with cancer and recognizing how much fear this terrible disease causes. How these invading cells try to take over our bodies and our life.

Whether you are the patient, a caregiver or part of the patient’s support group of family and friends, you can show who is in control – YOU!

We have developed a line of merchandise and apparel with the Cancer Fears Me logo to help fund our programs for the Cool Kids Campaign, including the Cool Kids Connection.

Check out our website at www.cancerfearsme.org.

Check out our Cancer Fears Me video on You Tube! Just search for Cancer Fears Me.