How would you react when faced with adversity or a health scare? What distance would you go when a family or friend is faced with their toughest challenge yet? What are you made of? What is your wingspan?

We are the Crockett-Carrington family: Khia Carrington and Erin Crockett, a two-mom family with two children, Ethan, 7; Emery, 5; and a dog named Morocco. We enjoy camping and traveling.

July 10, 2019 - We had arrived at Niagara Falls in Canada after driving for eight hours. We pulled in our RV and were ready to meet up with our Canadian family, who were enjoying the pool area. We changed the kids, Khia guided them to the pool, and I set up the RV. An hour later, I joined them and noticed Ethan was not acting himself; he was off to the side and not interacting with his sister or the other children.

Later we walked back to our campsite. Ethan complained of body aches, began to cry, and wanted me to carry him. We gave him Motrin and researched Canadian hospitals in case of an emergency. That evening we stay in our campsite instead of sightseeing. Ethan's pains came and went. The next morning, he played on the bed as if the pain had never existed.

July 20, 2019 - A week after our return home, we were at a family graduation party and barbeque. Ethan danced and swam – he and Emery had a blast – but that night while putting the kids to bed, Ethan's pain had returned, along with severe leg cramps. We called our pediatrician who said it sounded like growing pains, muscle spasms, and/or dehydration. Because it lasted through the night, we took our son to the hospital the following day. Bloodwork was done, fluids were given, and he was treated for dehydration and sent home. But the pain didn’t stop and Ethan complained his entire body hurt. He even stopped walking.

Following up with the pediatrician, Ethan just laid on the table while being examined. The doctor suggested we bring him back in a few days, but we decided to take him back to the ER. Looking at Ethan's photo, I noticed the painting's words: “There is always hope.” Little did we know the impact of those words.

July 26, 2019 - We rushed Ethan to the hospital for additional bloodwork. Now having a baseline, they were able to see his white blood count was much different. I had gone to pick up Emery from daycare when Khia called. She said to come back. I knew it was something more than dehydration, so I begged and demanded she tell me.

We will never forget that day. Somehow, I made it to Emery's school. With the Assistant Director at my side, I broke down, relaying that the ER doctors said Ethan's results were consistent with cancer and they wanted to transport us to Johns Hopkins Children's Hospital. We couldn't believe they said CANCER!

July 27, 2019 - On Ethan's seventh birthday, he was diagnosed with Pre-B Cell Acute Lymphoblastic Leukemia (ALL) with a standard risk. To confirm his diagnosis, they extracted bone marrow from both sides of his hips and had his first chemo injection in his spine as a preventive measure. He rested that Sunday; on Monday he received a PICC line in his arm which served as an IV and chemotherapy entry point. He also had spinal fluid extracted to test for leukemia in his spine and brain. We were so thankful to learn no immature white blood cells were found.

A few days later, once the doctors examined the cells, we received a treatment plan: Induction Phase (first stage, 28 days) to receive the hard-hitting chemo. Next, another spinal puncture and bone marrow biopsy to ensure there was no trace of the leukemia cells. Typically, there is no trace after the first phase ... Ethan was in remission!

(continued on page 10)
LETTER FROM THE PRESIDENT

Dear Cool Kids Families,

As we enter 2020, it is exciting to be celebrating this 40th Edition of the Cool Kids Connection Newspaper with you! Since 2007 this one-of-a-kind paper has been published and mailed free of charge to pediatric children’s hospitals nationwide and is included in our Care Packages for newly diagnosed patients. The goal has, and always will be, to connect you to each other as you journey through the shared experience of pediatric cancer.

Each day, approximately 43 children are diagnosed with cancer and our desire is to have every one of you become a part of the Cool Kids family! Our mission is to improve the lives of pediatric oncology patients through free academic, emotional and social programming. Our Connection newspaper is one way we do that so we want to hear from you. Afterall, you are the reason we exist and who better to tell your stories than YOU!

Thank you for allowing Cool Kids to serve families like yours. It has been one of my life’s greatest pleasures to be a part of your lives in this way. Cool Kids is continuing to grow and I look forward to our next chapter and to hearing more from all of you. Best wishes for a wonderful year ahead!

Chris Federico
President & Founder
“This is truly a dream come true” said Chris Federico, President & Founder of the Cool Kids Campaign Foundation at the January 25th Grand Opening for its new Cool Kids Clubhouse located just outside of Charlotte, in Huntersville, North Carolina.

“It seems like yesterday when I nervously but excitedly opened the doors of our first clubhouse. I always envisioned more than one and now here we are” he said. The new clubhouse, modeled after the flagship Clubhouse located in the suburbs of Baltimore, Maryland, is a sign of growth for this emerging organization which aims to “support the coolest kids fighting cancer” through its mission to improve the quality of life for pediatric oncology patients through free academic, social and emotional programming.

The Charlotte Clubhouse is named in honor of Olympic Gold Medalist Speedskater, Dan Jansen, who, in the aftermath of losing his own sister to leukemia, started his own foundation. One aspect of The Dan Jansen Foundation helps to support the financial needs of pediatric oncology patients in the greater Charlotte area and beyond. Over the past six years, the two foundations have partnered together at the annual Dan Jansen Celebrity Golf Classic to raise awareness and funds to support their respective and like-minded programs. As a result, Cool Kids purchased a care condo in 2017 to support families undergoing long term treatment with temporary housing from the two area hospitals. It was a natural fit to bring together the two organizations to support the opening of a Clubhouse that serves the needs of children with cancer from both the Levine and Hemby Children’s Hospitals.

With high hopes ahead, and three new staff members for the Charlotte Clubhouse, Cool Kids is well on its way to positively impacting children with cancer in the community. The staff is already visiting one of the hospitals each month providing lunch and craft activities during clinic hours. The clubhouse will host its first movie night on Saturday, February 29th where parents can drop their kids off for a few hours of fun with crafts, dinner and a movie.
Future programs will include Smile Celebrations for milestone achievements, Parent Drop of Days, Tutoring, Support Groups and more. “We are excited for the opportunity to serve families in the greater Charlotte area. We hope that our clubhouse becomes the place where kids with cancer can truly be themselves” said, Melissa Scott, the new Managing Director. She will be heading up program development, fundraising, special events and staff management. At the grand opening Cool Kids was able to welcome several local families to visit the clubhouse for the first time.

With over 120 attendees at the grand opening event we are sure Cool Kids is off to a great start! With a strong committee of volunteers and supporters we believe the Clubhouse will usher in a new wave of support services for families caring for children with cancer. Dan Jansen shared how honored he was to have the clubhouse named after him. “The fact that the clubhouse is being named in my honor is humbling” says Jansen. “It’s emotional and there really are no words to express what it means to me. I’m not going anywhere so we will continue to move forward with Cool Kids together.”

As the grand opening event ends the real work of fundraising and developing local programs begins. What we know for sure it that the new clubhouse certainly will be a very cool place for some very cool kids!
The brand-new zookeeper was getting ready to put new labels on all the animal exhibits when suddenly he dropped all the letters. Can you help him unscramble the words below so the zoo visitors will know which animal is which?

**Find the Hidden Pictures**

**Find:**
- glasses
- camera
- binoculars
- map
- car
- airplane
- dolphin
- dinosaur
- fish
- monkey
- giraffe
- penguins
- polar bear
- porcupine
- fish
- gibbon
- reindeer
- zebra
- sharks
- insects
- frogs
- rhinoceros

**AT THE ZOO**

The brand-new zookeeper was getting ready to put new labels on all the animal exhibits when suddenly he dropped all the letters. Can you help him unscramble the words below so the zoo visitors will know which animal is which?

NLOI ______  EESTPNALH ______  HISF ______
RLUTTE ______  PDALEOR ______  BIGBON ______
KAESNS ______  RROTGA ______  RREENID ______
LOW ______  LKAALO ______  BZREA ______
EHCTEHKA ______  RAEGFIF ______  KSSRAH ______
GREIT ______  GPEUNINS ______  SINCTSE ______
KOMEYNA ______  LAORP ERAB ______  GORSF ______
RABE ______  CURPOENIP ______  SRCNHROEO ______

**Answers:** Lion, Turtle, Snakes, Owl, Cheetah, Tiger, Monkey, Bear, Elephant, Leopards, Parrot, Koala, Giraffe, Penguins
HELP THE MOMMY ELEPHANT
FIND HER BABY!

PICTURE PUZZLER
If you find the correct letter for each clue, you will spell a word that should make you happy!

1. Find a letter that is in ☞ but not in ☜ __
2. Find a letter that is in ☜ but not in ☞ __
3. Find a letter that is in ☜ but not in ☞ __
4. Find the letter that is in ☞ but not in ☜ __
5. Find a letter that is in ☜ but not in ☞ __

Write your letters again here to spell a word that should make you happy: ____  ____  ____  ____  ____

Answer: The happy word is SMILE
A shrimp's heart is in its head.

Some lipsticks contain fish scales.

Like fingerprints, everyone's tongue print is different.

Rubber bands last longer when refrigerated.

A crocodile cannot stick its tongue out.

There are 293 ways to make change for a dollar.

"Dreamt" is the only English word that ends in the letters "mt".

Cat urine glows under a black-light.

A shark is the only known fish that can blink with both eyes.

It is physically impossible for pigs to look up into the sky.

If you sneeze too hard, you could fracture a rib.

It is impossible for most people to lick their own elbow. (try it!)
PUT YOUR THINKING CAP ON TO SOLVE THESE RIDDLES!

a) Billy’s mother had five children. The first was named Lala, the second was named Lele, the third was named Lili, the fourth was named Lolo. What was the fifth child named?

b) Choose the correct sentence: “the yolk of the egg is white” or “the yolk of the egg are white.”

c) It’s as light as a feather, but the strongest person can’t hold it for more than five minutes. What is it?

d) The more there is, the less you see. What is it?

e) What gets more wet while it dries?

f) You can find it in Mercury, Earth, Mars, Jupiter and Saturn, but not in Venus or Neptune. What is it?

g) It likes food, but water kills it. What is it?

h) What’s full of holes but can still hold water?

i) Which is heavier, a pound of feathers or a pound of rocks?

j) How far can a dog run into the woods?

k) You’re driving a city bus. At the first stop, three women get on. At the second stop, one woman gets off and a man gets on. At the third stop, two children get on. The bus is blue and it’s raining outside in December. What color is the bus driver’s hair?

l) There are three houses. One is red, one is blue and one is white. If the red house is to the left of the house in the middle, and the blue house is to the right of the house in the middle, where’s the white house?

m) It’s at the center of gravity and you can find it in Venus, but not Mars. What is it?

n) What goes on four feet in the morning, two in the afternoon and three in the evening? (This is from the classic myth, Oedipus and the Riddle of the Sphinx)

o) What travels faster: heat or cold?

p) A man was walking in the rain in the middle of nowhere without a coat or an umbrella. He got soaked, but not a single hair on his head was wet. How can this be?

q) A cowboy rode into town on Friday. He stayed in town for three days and rode back out on Friday. How is this possible?
A cancer diagnosis has a profound effect on anyone, especially when it is a child who has been diagnosed. Children face unique challenges and adjustments. It helps to talk to your child about what they can expect and encourage them to share their feelings.

Talk It Through. Give age-appropriate, accurate and honest information about your child’s diagnosis. Don’t be afraid to use the word “cancer.” While adults often associate fear with the word, children feel secure knowing what their illness is called. Answer your child’s questions honestly. You can be realistic while remaining hopeful. Encourage your child to ask questions throughout their treatment. If you do not know the answer to a question, don’t be afraid to say “I don’t know. I will try to find out.”

Prepare Your Child. Explain the treatment plan and how it will affect their life. Prepare your child for physical changes he or she may experience during treatment (for instance, hair loss, fatigue, or weight loss). This will minimize surprise and provide an opportunity for your child to ask questions and prepare for the changes he or she may face.

Reassure Your Child. Let your child know that he or she will be taken care of by their medical team and that you will continue to support them. While your child knows that you love them, during this time they may ask for or need more reassurance since they are feeling vulnerable. As always, continue to let your child know that you are there to take care of them and that you and their doctors will be working to help them feel better.

What to Say. Discuss language your child feels comfortable using when responding to questions from peers. Your child’s classmates and friends may ask your child questions about his or her illness. You can preemptively prepare your child for this by discussing how he or she feels most comfortable responding. While some children would rather not discuss their diagnosis with classmates, others may wish to be more open with peers. Understanding your child’s specific wishes can help inform the way you and the child’s teachers support your child.

Encourage Your Child to Express Their Feelings. Let them know that all feelings are acceptable and that sharing their feelings can help them feel better. Explain that feelings can be expressed in many different ways such as talking, writing in a journal and drawing or by engaging in an active sport such as running or hitting a punching bag. Let them know that it’s also okay to say, “I don’t want to talk right now.”

It’s a Team Effort. Collaborate with your child’s teacher, school social worker and nurse. Meet with them to discuss your child’s medical and educational needs. Identify a school liaison. He or she can be the point person for you to speak with regarding your child’s school work and health matters. The school liaison can also be in contact with your child’s medical team to create a contagious disease plan. Once you have developed this plan, speak with the school liaison about informing classmates’ parents about the necessary protocol should their child become sick.

Support for You. As a parent and caregiver, it can be easy to forget about your own needs. Remember that in order to be there for your child, you need to take care of your own physical and emotional needs. Find time to practice self-care, even in small ways such as taking a walk around the block, talking with a friend or doing something you enjoy. By caring for yourself, you will also be modeling healthy behavior for your child.

Reach out. Help your child identify the adults they feel most comfortable turning to for support. These people may include you, your spouse or partner, relatives, friends, clergy, teachers, coaches and members of your health care team. You may also want to speak with your hospital social worker about local counseling and support services for children with cancer.

Support Groups. Connecting with other children who have cancer can help your child feel less alone with their diagnosis. Joining a support group for parents who have a child with cancer can help you feel less alone in your journey as well. Speak to your hospital social worker about local support groups or call 800-813-HOPE (4673) to speak with a CancerCare oncology social worker about support services available to you.
After 28 days, a port was placed in Ethan's chest and the PICC removed. The port would allow him eventually to swim, participate in karate, and live without physical restrictions. Weekly chemo in the outpatient clinic would begin at Johns Hopkins – two-and-a-half years in length.

It has been a tough, long road, yet Ethan has proven what it means to be #EthanStrong – firm and strong. No exaggeration there! The difficult part was convincing our son to realize just how strong he was actually ... and to understand how strong he would need to remain!

How do you move forward to live your best life as you wonder your capabilities and the width of your wingspan?

- Don’t focus on what won’t serve you. Instead focus on your blessings
- Remain in gratitude. We thanked every nurse and doctor that treated Ethan and told them they were the best at what they do. We wanted them to know we saw them and appreciated their hard work. God placed everyone in our lives for a reason.
- Bless others through your storm; it will allow you to free your mind from the situation and help others to smile. Ethan's grandparents purchased Legos for him to hand out at clinic – a great lesson for him! Your blessing can be other than monetary, such as a heart-filled conversation.
- Allow the shock to set in: receive the news, process it, allow yourself to cry and scream. Get it out of your system, then research the diagnosis and learn the treatment plan for your child.
- Take deep breaths. Take one step at a time. This pill is too large to swallow, so cut it into tiny pieces and digest it bit by bit.
- If someone offers help – accept it – don’t wait until you’ve reached rock bottom. Push the pride out of the way. We generated PayPal, CashApp, Venmo, Zelle, and amazon wish list accounts, which made it easy for people to donate – they rolled in. The help from others can help you not to feel so Ask for what you need; if you are so overwhelmed you can’t think, find a facebook group to ask others who have been there. Use your resources!
- We decided not to cry in front of Ethan because we didn’t want him to feel afraid, too.
- Take breaks – individually and together.
- Keep the lines of communication wide open between both parents. If yours is a one-parent household, open a line of communication between trusted family or friends.
- If you have other children, be sure to give them quality time. The sick child will naturally receive a great deal of attention, time, and things from you, others, and the hospital staff.
- Keep daily life as normal as possible, such as routines and playdates, especially for siblings.
- Be a blessing to others in treatment. Melanie and Ray from Cool Kids Campaign came over without hesitation, having been down the same cancer road. They knew exactly how we felt and what we needed to hear.

The ultimate measure of any human is not where they stand in moments of comfort and convenience, but where they stand during times of challenge, valleys and controversy. That's when you'll learn exactly how wide is your wingspan.
Am I So Different?
~Author Unknown

Am I so different because I've lost my hair, is that the reason you feel a need to stare, am I so different because of things I cannot do, does that really make me less normal than you,

Am I so different, so different from you, is making me uncomfortable a pleasure for you, if my looks are upsetting to one and all, just try and remember that my life is no fun at all,

You see me like this and wince as I pass by, never once do you notice the tear in my eye, it's not illness or pain that makes me cry, its your stares and snide comments as I walk by,

So, please, I implore you, take this to heart, I am truly human, not a species apart, this illness is my burden, a heavy one too, if not for a misfortune, this me could be you,

My life is now a battle, this cancer I must fight, your cruel and hurtful prattle, pains me day and night, instead of pain and sorrow, give me your smile that's true and bright, walk with me through each tomorrow, don't shun me out of fright.

Cancer Relapse Statistics:

- 15-20% of children with ALL
- 40% of children with AML
- 50% of children with neuroblastoma
Send us your stories, art, poetry, and photos and become a published writer or artist!

Email all submissions to:
melanie@coolkidscampaign.org
or mail to:
Cool Kids Campaign
8422 Bellona Lane, Suite 102
Towson, MD 21204

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

410-560-1770
8422 Bellona Lane, Suite 102, Towson, MD 21204

CANCER FEARS ME T-SHIRTS
Shirts are black - 100% cotton. Please mark boxes with quantity desired, not an x.

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CONTACT NAME ________________________________________________________________
SHIPPING ADDRESS ________________________________________________________________________________________________
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PAYMENT - Checks made out to ‘Cool Kids Campaign’ are preferred
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Phone: 410-560-1770 Fax: 410-560-1775 Email: Janet@coolkidscampaign.org

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