Help our kids grow old
By Annika Warrior Princess’ Momma, Salt Lake City, Utah

Today my 18-month-old daughter was released from the ICU after a major surgery to remove cancer from her tiny body. She was diagnosed with stage 4 Neuroblastoma when she was just 10 weeks old. She has endured 12 rounds of chemo, several biopsies, and the devastation of a relapse. She is doing amazingly well and exceeding doctors’ expectations with how quickly she is healing from the surgery.

It is only now that I am finally allowing my first tears to fall, and they won’t stop. Why now? Adrenaline can carry you through difficult situations, but the letdown comes when you sometimes allow yourself to process.

I’m including a photo of Annika in the hospital bed – one that I thought I wouldn’t share for a long time, yet today I feel compelled to share it. You see, when my daughter was in the ICU, rooms surrounding hers were occupied by adults also fighting cancer. The waiting room for the ICU was full of crying families. One particular family was losing their 92-year-old grandfather to cancer. I can relate, as I was equally devastated when my grandfather passed away.

What really resonated with me, however, was the sharp contrast between our situations. That grandfather had lived a full life, during which he had children, hopefully fallen in love, taken trips around the world, and perhaps graduated high school and college. My 18-month-old has never experienced a day outside my womb when her body wasn’t fighting the beast known as cancer. She hasn’t had the chance yet to have her first day of school or fall in love. Yet she fights for her life.

This is also where the Cool Kids Campaign’s Cancer Fears ME! slogan helps me! It reminds me that although cancer is a force to be reckoned with, the power that my tiny daughter possesses is powerful, too! The reason I am sharing this picture is because these children need our help, and I need to be brave enough to show what childhood cancer really looks like. People associate childhood cancer with happy, smiling, bald kids of which we always see pictures. We, their parents, are the only voices they have. We need to continue working toward a cure for our little heroes. I know that current research won’t help my daughter. I have to rely on treatment that past cancer families have fought for. Just as it’s possible that an undiagnosed child may benefit from the research dollars for which I have fought.

I know childhood cancer isn’t glamorous and is hard to stomach. But it is time – that instead of turning away from it – people realize that strength and comfort will come from their work and will make a difference in the lives of these cancer cuties.

If you are fortunate enough not to have a sick child, please do something to help. Donate to a worthy childhood cancer organization, or simply wear a gold ribbon on your shirt to help raise awareness. Help Them Grow Old, Wear Gold.

If your family has been affected by pediatric cancer, share your story. People need to know what our children are going through.

I would like to thank the helping hands that have helped to carry us along our journey. My amazing friends – the parents of The Utah Cancer Cuties; the amazing doctors and staff at my daughter’s hospital; Elliot and Annie our favorite therapy dogs; our knowledgeable and patient home nurse, Dylan, and of course, my wonderful family and friends. We couldn’t do this without all of you by our side.

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Help Them Grow Old, Wear Gold.

“People need to know what our children are going through.”
I firmly believe with the right mindset anything can be done. In my experience with ovarian cancer, I realized that would define me no matter what happens. Cancer is scary, it’s true, because until a cure is found it still represents the unknown, something we can’t control.

One thing everyone can control is how they face the situation. It was almost two years ago at age 14 that I was diagnosed with type one ovarian cancer. I had already had my tumor removed when I thought I was going in just for a checkup; my doctor told me I had cancer and we needed to start chemo soon. If the chemo didn’t work, I would have about a year to live. I sat there, and honestly, all I could think about was losing my hair. I cried for a few minutes until realizing that crying was not solving anything and this was something I would just have to get through. Cancer was not going to rule my life or change me.

I was determined to win this battle and prove to everyone that cancer does not always mean death; it can become a new hope for life. I had to consider: ‘What if I do lose this battle?’ … ‘What if things don’t turn out like I plan?’ Then fine, I was not going to let that stop me from living now. There was no point in me sitting around and feeling sorry for myself when there were people out there who had it a thousand times worse than me. I was not only going to get through this for me, but I was going to do it for them. So, I delayed chemo until after Halloween because I really liked costumes. I was dressing up as a lemon and I was going to wear it!

Before chemo I decided to cut my hair really short and donate it since I wasn’t going to need it. Plus I wanted to get used to the feeling of not having much hair. That was really hard for me. As girls, I think we obsess over our hair and the things we think make us pretty. Honestly, I hated my short hair at first. I didn’t feel like myself. I think what truly bothered me about it was what it represented. I was so afraid for everyone to see that I was sick or that there was something wrong with me. I didn’t want people to see me or treat me any differently than anyone else. I think that’s the normalcy we all crave as things change. I didn’t want to be seen or known as sick. I refused to call myself - or let anyone else call me - sick. I would say that I was “simply not at my best.”

Since ovarian cancer could affect my ability to have children later in life, I had to take other precautions. I can’t even explain the looks I got as a 14-year-old sitting in the waiting room of a fertility clinic! :-)

Mattie Bayne, age 16
Baltimore, Maryland
Soon after, I started chemotherapy – which is simply terrible, to say the least! I think every cancer patient will agree that chemo sucks. I must say though, when you can finally eat after all of that – food never tasted so good. Three months after finishing chemo I was able to travel on my school’s trip to Argentina, where I had the time of my life. I really hope to go back one day. My host family knew about my cancer and was very supportive. I didn’t want anything to hold me back. I think cancer wears you, but you just come out stronger and more confident. When I entered remission I felt invincible – ready for the next battle. I was now at the top of the mountain! Cancer not only affects you, but everyone around you. The massive amount of love and support I received from everyone around me was incredible. I believe everything happens for a reason. If it wasn’t for my cancer I wouldn’t be as confident as I am today.

I couldn’t play basketball anymore, so I started helping backstage in the theatre community where I met some amazing people who I might not have had the chance to connect with otherwise. I’ve become more passionate about volleyball because I played on my club team through it all. Yes, I had to miss a few tournaments and practices, and wearing a wig while playing was not that easy, but it was worth it! I got to meet my favorite band, McFly, and attend some great concerts.

I joined the board of the Baltimore Women’s Classic, which is a race to support women with gynecological cancers; it’s held annually in June. I am also starting to get more involved with the National Ovarian Cancer Coalition. I think I am a better person today than I would have ever been having gone through the struggles and rewards of having cancer. People are always searching for the negative with cancer, yet with every opportunity or challenge with which you are presented; there can be something positive taken from it.

The three words I like to abide by are … mentality, patience and effort. While keeping those in mind, everything seems more doable. Cancer can make you or break you – refuse to be broken!
And once the storm is over, you won't remember how you made it through, how you managed to survive. You won't even be sure, whether the storm is really over. But one thing is certain. When you come out of the storm, you won't be the same person who walked in. That's what this storm's all about.

~ Haruki Murakami

The country that put a man on the moon can cure cancer.

We've always embraced big challenges in this country. It's how the world sees us. How we see ourselves.

Now, President Obama has called on us to end cancer in our lifetime. America’s pharmaceutical research and biotechnology companies share that goal. Today, our scientists are working on 800 new medicines to fight this deadly disease that touches so many lives.

It won’t be easy, and it won’t happen without a renewed emphasis on innovation and a sustained commitment to research and development. Last year, we invested more than $65 billion to discover and develop medicines to help patients live longer, healthier and more productive lives. Like President Obama, we believe that America’s best days are ahead of us. Working together, we can do anything.

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SURFIN’ THE NET...

Have you discovered a useful or fun website to share with other families dealing with pediatric cancer? Email the link to suzanne@coolkidscampaign.org for inclusion in the next issue of Cool Kids Connection. We found a few to share with you …

1. **Simply Sayin’™ (phone app)**
The medical jargon health care professionals use can be overwhelming to children, because they process information differently than adults. This app uses pictures, sounds and child-friendly glossary of terms to facilitate clear conversations between the healthcare provider, child, and family.

2. **LighthouseFamilyRetreat.org**
Retreats offered for families who have a child with cancer. Provides momentary normalcy in the midst of the chaos by allowing kids to just be kids … playing in the sand, laughing in the sun.

3. **Legos For Leukemia**
is a 100% volunteer community service project that delivers donated LEGO sets to children with cancer and other life-threatening diseases. Visit their facebook page at Legos for Leukemia.
Tyler was diagnosed with A.L.L. on February 29, 2008. He has been officially in remission since April 2010. The Gardners say they "pray every day that he has truly beaten this disease." Tyler has Down Syndrome and other special needs; he is also adopted. "He is such a joy and blessing in our family," says his mom Jodie. "He is pretty lovable. He has a great personality and he's full of spunk!"

As September winds down I can't help but feel frustrated and a little sad. September is Childhood Cancer Awareness Month. Just one month that is meant to support ALL of the childhood cancers: Leukemia, Neuroblastoma, Lymphoma, Ewing Sarcoma, Hodgkins Disease, Retinoblastoma ... and too many others. And we are supposed to somehow bring awareness to all these cancers in a single month.

October is here now. And the country will focus on breast cancer awareness. And that's fantastic! People will dress in pink and wear pink ribbons and participate in pink runs and walks. Football teams will wear pink jerseys. I'm pretty sure the White House and the Empire State Building even have pink lights. And I'm thankful for the awareness. Truly I am. I know many women who are breast cancer survivors. And it is because of all the steps that have been taken, the research, and the early mammograms that they have survived. And I am so, so thankful.

And yet, I can't help but wish that childhood cancer awareness was even half as important to others as is breast cancer awareness. I wish that the White House had gold lights. I wish that there was more money focused on childhood cancer research. I wish that more children could be saved.

I know too many families whose children have fought this horrible disease. I know too many families whose children have lost. Their faces will never leave me. Their amazing spirits will forever be a part of my life. I'm thankful to have known them. And as I look at Tyler and say a prayer of thanksgiving that he survived, I can't help but think of those who did not. And it breaks my heart a little bit every time.

So parents, kiss your children. Hug them tight. Say a prayer of gratitude that they are healthy and happy. And pray that someday the focus on childhood cancer research will be greater. Pray that more children can be saved. Pray that these awful diseases aren't allowed to claim another child.

Tyler was diagnosed with A.L.L. on February 29, 2008. He has been officially in remission since April 2010. The Gardners say they “pray every day that he has truly beaten this disease.” Tyler has Down Syndrome and other special needs; he is also adopted. “He is such a joy and blessing in our family,” says his mom Jodie. “He is pretty lovable. He has a great personality and he’s full of spunk!”
Thanksgiving Today

Across
3. Star of the Thanksgiving dinner.
6. Thanksgiving is often an occasion for a family ______.
8. Mashed ______.
11. Popular sauce.

Down
1. It would be hard to cook a turkey without one of these.
2. Most popular berry at Thanksgiving dinner.
4. Thanksgiving dinner is a popular, and old, American ______.
5. Game often watched on television after Thanksgiving dinner.
7. Thanksgiving turkeys are usually full of this.
9. Most people celebrate Thanksgiving with their ______.

ANSWERS
ACROSS- 3. TURKEY 6. REUNION 8. POTATOES 10. YAM 11. GRAVY
DOWN- 1. OVEN 2. CRANBERRY 4. TRADITION 5. FOOTBALL 7. STUFFING 8. PUMPKIN 9. FAMILY

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<th>Starburst</th>
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**Halloween Candy Word Search**

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START

HELP THE SQUIRREL GET TO THE ACORNS

END
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www.printactivities.com

www.mooseberrygraphics.com

8 coolkidscampaign.org
A THANK YOU NOTE

Dear Auntie ___________ (female name),

I want to thank you for sending me the ___________ (adjective) gift. I never had a/an ___________ (noun) before. I can use it to fix all my ___________ (plural noun).

It will also keep my ___________ (part of body) warm if we have any ___________ (adjective) weather.

Your ___________ (adjective) nephew,

____________(male name)

STEP BY STEP LESSONS

Want to become an expert in karate or kung fu? You can learn martial ___________ (plural noun) in three ___________ (adjective) lessons with Master ___________ ‘s (person in room) video. This ___________-selling (adjective) tape takes you step-by- ___________ (noun) through a series of ___________ (adjective) exercises guaranteed to develop ___________ (plural noun) in your body and make you strong as a/an ___________ (animal). In less than a week, you will be able to do 100 ___________ - ups (verb) a day, skip a jumping ___________ (noun) for an hour, and climb a/an ___________ (noun) without losing your ___________ (part of body). And believe it or not, by the end of the month, you’ll not only be eligible for a black ___________ (noun), but you’ll be capable of breaking a four-inch thick ___________ (noun) easily with your own two ___________ (part of body, plural).

Unscramble these HALLOWEEN words

1. fhgreitn
2. huatn
3. shcerec
4. holw
5. sokop
6. htgso
7. hciwt
8. sleotkne
9. myumm
10. aknfseeintr

SOLUTION:

Dear Auntie ___________ (female name),

I want to thank you for sending me the ___________ (adjective) gift. I never had a/an ___________ (noun) before. I can use it to fix all my ___________ (plural noun).

It will also keep my ___________ (part of body) warm if we have any ___________ (adjective) weather.

Your ___________ (adjective) nephew,

____________(male name)
TWISTIN’ THE TONGUE

- Linda-Lou Lambert loves lemon lollipop lipgloss.
- Fuzzy Wuzzy was a bear. Fuzzy Wuzzy had no hair. Fuzzy Wuzzy wasn’t fuzzy, was he?
- A noisy noise annoys an oyster.
- Willie Wilder went wild while we went wading in the water.
- The sixth sick sheik’s sixth sheep’s sick.

RIDDLIN’ AROUND!

Where does a boat go when it’s sick?
To the dock!

What does a dentist do during an earthquake?
She braces herself!

David’s father had three sons: Snap, Crackle, and ____?
David!

What starts with a P and ends with an E and has a million letters in it?
Post Office

What has two hands, a round face, always runs, but stays in place?
A clock

The turtle took two chocolates to Texas to teach Thomas to tie his boots. How many T’s in that?
There are two T’s in ‘that’!

KNOCK-KNOCK JOKES

Knock, knock
Who’s there?
Mikey.
Mikey who?
Mikey doesn’t fit in the keyhole!

Knock, knock
Who’s there?
Doris.
Doris who?
Doris locked, that’s why I’m knocking!

Knock, knock
Who’s there?
Cash.
Cash who?
No thanks, but I would like a peanut instead!

Have a unique knock-knock joke or another favorite joke? Email it to suzanne@coolkidscampaign.org and we’ll publish it in a future issue!
Ryan was a normal, happy, rambunctious little boy. He loved to run, ride his bike, and torment his little sister, Abby. In November 2012, he was diagnosed with Ewings Sarcoma ... a rare bone cancer. I am Ryan's grandmother and caregiver. I was by his side every step of the journey, and these are just a few of the things that I learned while I watched this precious child fight the fight for life.

I learned that you can smile through ANYTHING. There were a lot of tears and anguish, but those never lasted for long. Ryan hated getting his port accessed, and it was always a struggle to get it done. The tears would flow, the struggle to get him to hold still, the begging: “Please, Gramma, don’t let them do it!” Those tears would be gone in seconds after the port was accessed, to be replaced by Ryan’s brilliant smile. Through “pokeys” (daily shots he needed to help his blood build back up after chemo), through bouts of vomiting, through the times he was too weak to raise his head ... there was always that smile.

I have learned that no matter what I have going on in my life, there is always room to have compassion and love for others. No matter how sick or how tired Ryan was, he always asked about the other kids we met while being treated. He always said a prayer for them – every night.

I learned to adapt to change, and never complain about it. One of the hardest things in the fight with cancer is the fact that you can never plan anything. If you plan on going to the movies on a certain night, that is the night a fever will pop up. You end up at the Emergency Room instead of the movie theater. There were many times we had planned something fun for Ryan, and instead we had to go to the hospital or stay home because his blood counts were low. Never once did he cry or complain about it. He took the changes in stride and made the best of it all.

There are so many lessons I have learned from this brave boy ... but probably the biggest lesson of all was to keep on keeping on. Through months of pain, sickness, chemotherapy, radiation, and hospital stays, Ryan just kept on going. Some days he slept 20 hours or more. Some days there was no sleep at all. Some days were spent so sick that he could not lift his head off the pillow. Some days there was so much pain, all he could do was moan. Through it all, he never gave up. He never gave in.

I am proud of my little super hero. He fought a valiant fight – and for now he has won! On July 26, 2013, scans showed that the cancer was gone. Ewings Sarcoma has a nasty habit of recurring, and we do not know what the future will bring. But Ryan will face it with the same courage and strength that brought him through this battle.
Whether you’re a child, teenager or adult, the hospital can be a boring place, not to mention sometimes lonely. Most hospitals offer things to do, like libraries and TV rooms, however, it is best to find out before you go what a particular hospital has, so you know what to bring along. Here are some ideas to help pass the time and provide a little distraction.

### FOR CHILDREN
- Write stories or keep a diary.
- Design your own hospital on paper: what would it look like? What would it have in it?
- Produce a short movie using a video camera or phone app.
- Create greeting cards for other patients using coloring books, activities books, crayons, markers, and stickers.
- Do school work over the phone with a classmate.
- Play silly stuff like this: 1) Super Duper Models: cut out different body parts and faces from magazines and rearrange them to create new models. 2) Cotton Ball Toss: save the little cup in which the hospital disperses pills, and toss cotton balls into it. Move the cup farther and farther away as your skills improve. 3) Construct things out of toothpicks such as a small version of the Eiffel Tower.
- Learn new jokes from a joke book or magic tricks from a magic book then practice telling jokes and showing tricks to the hospital staff and your family.
- Use construction paper and colorful writing instruments to make wall hangings, a small book, or a poem to hang in your room or to give away to other kids.

### FOR ADULTS
- Teach your child a new card game which you may have played as a kid.
- Help your child or family member keep up with schoolwork.
- Rewrite or type your collection of loose recipes and organize them into recipe books.
- Help toddlers learn letters, colors, numbers and simple words using flashcards and children’s books.
- Start a new hobby like scrapbooking, guitar, jewelry-making or model-making.
- Start writing that ‘best-selling’ novel to get the idea out of your head and onto paper!
- Chat with friends and family anywhere in the world via Skype on your iPad or laptop. It’s free!
- Start an online diary or blog, or write in a journal, about your family’s experience. A website such as caringbridge.org allows you to update your family/friends easily without having to constantly repeat information. Consider submitting a story to this newspaper, Cool Kids Connection!
- Try a different way of doodling – it’s called Zentangle (zentangle.com) – even if you’re not an artist!
- Take daily walks to provide a change in scenery and allow your body to move, stretch, and exercise.
- Not all talk has to be centered on the medical aspect of a hospital stay. Learn about people by asking questions about hobbies and home lives.
- Make a list of things you’d like to do – and think of how you will treat yourself – when the hospital phase is over: a giant ice cream sundae, a pedicure, a long nap in your own bed.
Our goal with Cool Kids Connection is to connect families across America who are dealing with kids’ cancer. This newspaper is published for you and about you … including stories by you! Here's what we look for …

**STORIES** ~ Share your experience with other kids living with cancer. Or, write about any kid-related topic at all!

**ART** ~ Like to draw, paint, sketch, doodle, color? Send us your artwork to publish!

**POETRY** ~ Express yourself through poetry: rhyme it, don’t rhyme it; we'll take it happy, sad, goofy or serious!

**PHOTOS** ~ Introduce yourself through a photo – can be with family or friends, in the hospital, or doing your favorite thing at home!

**FAVORITES** ~ Share your favorite song, book, video game, app, movie, Facebook page, website or TV show … we’re listening!

**JOKES/RIDDLES** ~ Wanna help other kids chuckle? Share your favorite joke. Send riddles, puzzles, brain teasers, or even a word search that you made up!

**COOL CAREGIVER & COOL KID** ~ Each issue has a fun Q&A featuring a “cool kid” and his/her “cool caregiver.” What’s your favorite cereal? Do you like cats or dogs? If you were president, what would be your first law? Our list of fun questions is ready for YOU – and your favorite nurse, doctor, child life specialist or caregiver!

Let Us Print Your Stuff!

EMAIL submissions to suzanne@coolkidscampaign.org. You can also mail items to Cool Kids Campaign, 8422 Bellona Lane Suite 102, Towson MD 21204.

Note that we are unable to reprint copyrighted material, so be sure to send your original artwork and photos! All submission becomes the property of Cool Kids Campaign.

Since it is so likely that children will meet cruel enemies, let them at least have heard of brave knights and heroic courage.

~ C.S. Lewis
Dezirae Dominique Black  
Baltimore, MD

What grade are you in? 9th 
How old are you? 14 
If you wrote a book, what would it be about? My life – how my fight was with cancer, a family member I lost, etc. 
What do you want to be when you grow up? Work with medicine or sing and dance. 
Do you enjoy playing and/or watching sports? If so, which is your favorite? Basketball – I enjoy playing and watching it. 
Favorite team? Miami Heat and Boston Celtics 
Do you have brothers and sisters? My brother Juan, 19; and my sister Alexia, 15 
What do you like to do for fun? Hang out with friends, go out, play sports, sing and dance. 
How do you like to help others? I like helping elderly people and giving to the homeless. 
Favorite cereal? Fruity Pebbles 
Favorite snack? Ice cream 
Favorite animal? Puppies 
Favorite subject in school? Math 
Who’s your BFF? Naem, Alexia, Kasey, Jordyn, Ashley 
Who is your favorite celebrity and why? Mindless Behavior, because I love how different they are and their personalities. 
What activities do you like to do for exercise? Track & Field 
If you were the President of the United States, what would be the first law you would make? I would change the driving laws. 
Favorite TV show? Bernie Mac 
Favorite video game? Call of Duty; Guitar Hero 
Favorite board game? Monopoly 
If you were stranded on an island, what 3 things would you have with you? Phone, friend, food and water (Hey now, Dezirae, that’s 4 things!) 
If you were a Seven Dwarf, which one would you be? Sleepy 
If you could meet someone famous, who would it be? What question would you ask him first? Kurt Cobain from Nirvana. If he was still alive, I would ask him, “What made you turn your life around?” 
What are you most grateful for? My family and friends and most of all, God, for getting me through my illness and beating cancer.

Erica Fried, RN, BSN  
Baltimore, MD

In what hospital and department do you work? Sinai Hospital of Baltimore, Pediatric Hematology/Oncology 
What is your job title? Nurse Clinician 
What do you do specifically? I work with kids with cancer and blood disorders. 
Favorite part of your job? Being able to spend time with my patients and being able to make them laugh. 
Least favorite part? Having to do certain procedures that make our patients cry or might make them sad. 
Favorite sport to watch and/or play? Football and hockey 
Favorite team? The Baltimore Ravens 
Are you married and/or have children? No 
What do you enjoy doing for fun? Spending time at the beach 
Favorite movie? Pitch Perfect 
Favorite TV show? Duck Dynasty and The Big Bang Theory 
Do you like cats or dogs? Dogs 
What’s on your iPod? A mix of everything 
Favorite book? I love reading magazines such as People and In Style. 
Favorite board game? Chutes & Ladders 
Favorite season? Summer 
Favorite cereal? Cinnamon Life 
Favorite fruit? Watermelon 
What celebrity do you admire and why? Sandra Bullock; she comes across as very pure. 
If you were a Seven Dwarf, which one would you be? Sneezy 
If you could have dinner with one person (alive or deceased) who would it be, and why? My Grandpa Howard (my mom’s dad). I never was given the chance to meet him and I hear he was an amazingly sweet and loving person.
Artwork from one of our cool kids, Millie (who was featured in our Fall 2012 issue). The website “P.S. I Adore You” (psiadoreyou.com) is holding a Cure the Kids campaign and Millie’s family (from Utah) says they are thrilled to be a part. In June, Millie at age 7, earned her angel wings, yet her artwork is now helping her dear friend Cami fight cancer for the second time. Millie’s family is offering various pieces of her artwork on the site to help raise funds for Cami’s family, also in Utah.

LET US FEATURE YOUR CHILD’S ARTWORK HERE!
Submit an illustration drawn by your child with cancer to suzanne@coolkidscampaign.org

McCormick is proud to support
Cool Kids Campaign
COOL KIDS WE LOVE

Send us YOUR photo to publish here! Email photo, name, city/state to suzanne@coolkidscampaign.org or mail to our address on page 2.

Shop for a Cancer Fears Me® temporary tattoo and other Cancer Fears Me® merchandise at cancerfearsme.org

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