

Making A Home Away From Home

By Princecine and Kurt Myers

To say we have a lot of experience living away from home would be accurate as a dual military family with over 40 combined years military experience. However, living away from our families and our home has never been easy especially when our only child has cancer.

Spring 2022

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In February 2019 our household goods and our cars had been shipped to our next duty station as we embarked on yet another (PCS) military move. We were moving from Monterey, CA with the plan of going to Pensacola, FL for a month, Augusta, GA for 6 months, and finally settling in MD on 3 year orders. However, before reaching Pensacola we stopped in TX to visit family when our sweet 2 year old daughter Ailani was diagnosed with Acute Lymphoblastic Leukemia.

The Navy immediately assigned us new orders to TX. But after about 6 weeks in TX the hospital realized they were not equipped to treat Ailani's aggressive and rare type of leukemia and suggested we transfer to a bigger hospital. In May 2019, after getting a new set of orders to MD, we hopped on a plane headed to Johns Hopkins Children's Hospital with nothing but our 2 suitcases of clothes we had from CA.

After 3-4 days in a local hotel we were approved to move into the Ronald McDonald house which was a beautiful brand new facility. That was almost 3 years ago and unfortunately we have had to move around a few more times for Ailani's treatment. She has now been treated at four different hospitals in four different states.

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ABOUT THIS ISSUE

This month's issue is dedicated to managing some of the challenges that may accompany your child's cancer diagnosis. For some families, this means moving to a new location to be near a hospital where specialized services are available. This is a huge disruptor that makes an already challenging time even more stressful. In our cover article, Cool Kids parents Princecine and Kurt Meyers share their extensive experience and tips for making the move more manageable while keeping things under control back home.

We also share information from our friends Kids & Art, a non-profit that offers free online art workshop for kids with cancer. They provide art experiences that can be both therapeutic and easily accessible from hospital room or home. Experiences such as the ones they offer can help normalize your child's environment and provide something to look forward to.

Even if you are not moving across country, you need comfort everywhere you can find it. Our friends at Weis market have provided some tips for creating healthier comfort foods.

And finally, we are excited to invite young childhood cancer patients and survivors to participate in our coloring contest! Your child can win a beautiful handmade ladybug quilt kindly donated to us by the Faithful Circle Quilters in Columbia, Maryland.

We hope you enjoy this issue. Would you like access to more online content and resources? Sign up for our national email newsletter by emailing renee@coolkidscampaign.org.

Happy Spring!

EMOTIONAL SUPPORT FOR KIDS WITH CANCER

The physical symptoms of cancer, and the treatment of it, can have serious social and emotional consequences for the child. Research indicates that the negative perception of self-appearance often found in children with cancer is associated with academic, social and psychological impairment, low self-esteem and symptoms of depression.*

At our Cool Kids Clubhouses, we offer programs that allow kids treated for cancer to be themselves among others who share their life experience. Our programs include Movie Nights, Smile Celebrations honoring a birthday or treatment milestone, Teen Nights, camp days; Halloween celebrations, holiday parties and more. If you are in the Baltimore, MD or Charlotte, NC area, please join us for a Clubhouse event. Not in our area? Sign up to receive links to great online programming! renee@coolkidscampaign.org

You can find recorded presentations on nutrition, bullying and pediatric cancer, chemobrain and learning and more on the Resource Page of our website: www.coolkidscampaign.org.

*Psychological Impact of Childhood Cancer; Annie Toro, J.D., M.P.H; Public Interest Government Relations Office; American Psychological Association





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We've had fellow cancer parents ask us how we do it and honestly I think a lot of it is because of our military background. We understand that we are in battle to try and cure our daughter whatever the cost

may be. We pack up and move where we need to go for Ailani's treatment just as if the military gave us 24 hours notice to move out for battle.

Here are a few items of advice we can offer to other families living away from home for treatment or those that may have to travel to a new hospital for treatment.

Remember WHY you are away from home. It's to win the battle for your child! It will be hard, it will definitely be a challenge being away from your support system, but the end result is worth it when your child is in remission! You will make a new support system whenever you go!

Here are some pointers to help you establish and leverage your support system:

1. Develop a relationship with the hospital social worker! Don't be afraid to ask for what you and your family may need. They will have some resources that can help with living arrangements, activities/toys for your kids, they may have names of local organizations/charities that will assist financially or with food items. They may not know everything but they can get you pointed in the right direction so you can further research things for yourself.
2. Talk to other cancer families! One of the biggest helps we have found is talking to other cancer families in the hospital, Ronald McDonald House, and social media (Facebook groups are amazing). Everyone is so willing to share information about organizations/foundations that will help with various things, as well as share different experiences about treatments, side effects, medications, and clinical trials.
3. Reach out to cancer organizations and foundations! The Leukemia and Lymphoma Society can assist with searching clinical trials. You can tell them where you are willing to travel. Other more local organizations can possibly provide you with lodging and essentials while away from home. Again, hospital social workers should have general familiarity with local organizations and foundations that can offer support. If you are traveling very far from home to a new hospital, even across the country, there are organizations that can help you with flights. Some can even charter free private flights for you and your child if there are safety concerns with flying commercially. AeroAngel and Children's Flight of Hope are both great organizations and they work quickly.
4. Check with your insurance company about travel benefits. Insurance companies may reimburse payment for lodging, rental car, and meals. Some insurance companies will pay for all or some of these expenses. Figure out what paperwork needs to be submitted for reimbursement before you travel. That way you can fill it out day by day instead of at the end of your trip. Make sure you save your receipts as credit card statements are often not enough proof of expenses. We had no idea about this on our first move and we spent a ton of money out of pocket moving across the country, paying to ship our cars, for lodging, food and everything else.
5. Notify the post office to hold or forward your mail. Most post offices will only hold mail for 30 days although if you explain your situation, the post office may hold for longer. If you need mail held longer than 30 days, you can sign up to have your mail forwarded. If you're having your mail held, give the post office authorization for a relative/friend to pick up your mail from the post office. Have that person check your home mail as you may receive parcels from UPS, Fedex, etc.
6. Prepare your house for travel. Turn off the main water valve to the house. If a pipe breaks while you're not home for days, weeks, or months, that would definitely be a disaster. Put a few lights on timers to make it appear as if the house is occupied. Tell a trusted neighbor you'll be gone and ensure they have your number so they can reach out if they see anything unusual or concerning. Ask a trusted friend or family member to check on your house weekly while your away. They can check for any water leaks, uninvited animal or bug problems, or anything else that may be out of place.
7. Have someone check on your cars every few weeks. Have them start the engines and let them run for a few minutes so the batteries are not dead when you return.
8. Have someone keep pets for you instead of paying for pet boarding. We unfortunately had to make the difficult decision to rehome our labrador retriever when our daughter got sick. Fortunately, our daughter's grandparents love the dog, take great care of her, and can deal with the hair shedding.
9. Prior to returning home have Professional cleaners or relatives come and clean and dust your house. There is a cancer organization that offers this service for free called Cleaning For A Reason.
10. If friends ask what they can do to help. Ask for gift cards to restaurants, food delivery apps or gas cards. When you are away from home and or in the hospital, you will be eating a lot of take-out.

Moving is hard, being away from family and friends is hard, childhood cancer is even harder. We've been on this cancer journey for 3 years now and it is extremely exhausting and also very lonely. We have no family here in MD, we haven't seen our immediate family in 3 years. We are in battle to try and save our only child from cancer which is our number 1 priority!





Cool Kids would like to introduce you to some of our friends!

THIS MONTH WE SPOTLIGHT:

kids &
art

healing pediatric cancer
through the arts

Words are often not enough to feel seen by the world or to have the world see us. Faced with a life-altering circumstance, a void of expression can feel almost as difficult and isolating as the experience itself. This can be especially challenging for a child confronting a cancer diagnosis. It's no less true for their loved ones and family members. The simple act of making art offers an often forgotten avenue of healing expression, exploration, and play—drawing out ineffable and powerful emotions—while requiring no explanation. The internal becomes external and seen: free to connect, grieve, or celebrate.

OUR MISSION

At the Kids & Art Foundation, we use art to empower, encourage, heal, and create memorable experiences. We do this by using the power of the arts and creativity to mitigate stress, anxiety, and trauma induced by diagnosis and treatment.

The group was founded in 2008 by Purvi Shah, a parent whose child was diagnosed with cancer at age three, then lost his life six years later, after she saw the healing impact moments of art and creativity had on her family while her son was in treatment. What began as one family's joyful escape through art is now a creative escape for many.

REACHING PATIENT FAMILIES IN THEIR VIRTUAL BUBBLES

Pediatric cancer and other critical medical conditions do not stop for anything, not even Covid-19, so neither could we. While we have all had to learn to adapt and live with the pandemic, and its impact on our "normal lives" and mental, emotional, and interpersonal health—our pediatric families fighting cancer and other critical medical conditions live this upside down and challenging life daily.

In 2021, we found ourselves with an added responsibility to reach our patient families where they were, not only in their treatment cycle but also in their virtual bubble. With innovation and resourcefulness, Kids & Art was able to continue bringing the power of creativity and art to pediatric patients and healthcare providers through our online art workshops. This allowed each participant to have a healing art experience while working in a group or 1:1 setting with a lead artist, easing some of the isolation pediatric patients experience. Our focus was on creat-

ing a series of workshops that offered our families a diverse collection of art projects and experiences.

LET'S HAVE SOME FUN!

Mental stress can stop us in our tracks. Some of the known benefits of coloring (for kids AND adults) include: Relaxing your brain and improving brain function, inducing a meditative state, improving motor skills, improving sleep, improving focus, reducing anxiety, and relieving stress.

Over the years we've made and used coloring pages based on artwork by our patient artists. We want to share one with you here. Please enjoy—and color!

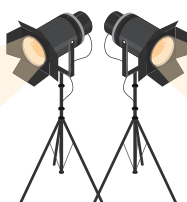
You can sign up for our monthly online art workshops here:
www.kidsandart.org/online-workshops



AMAEYZING ARTKITS

We also created our Amaeyzing ArtKits, a blend of art and wellness projects designed for kids aged 4+ years, keeping in mind the special needs of children and families in critical medical situations. They are intended to offer independent art experiences, accessible whenever it best serves the patient and family as a creative arts support, whether at home or in a treatment center.

Each Amaeyzing ArtKit includes all instructions and supplies needed to engage in the art project experience, as well as a QR code for access to a pre-recorded artist guide video.



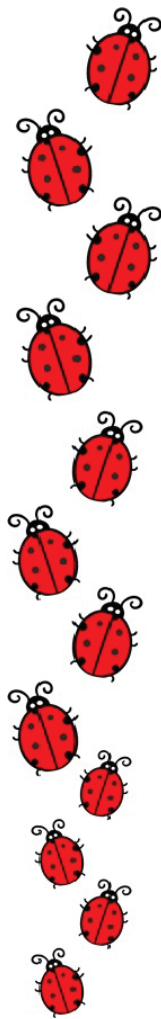
PUZZLES AND GAMES

Parts of a Ladybug

Use the code in the yellow boxes below to spell out the parts of a ladybug's body. Color the ladybug when you're done!

Ladybug Word Search

The words appear up, down, backwards, and diagonally. Find and circle each word.



- ADULT
- BEETLE
- BLACK
- BRIGHT
- COLORS
- CROPS
- CUTE
- EAT
- EGG
- ELYTRA
- FLY
- GARDEN
- INSECT
- LARVA
- LEGS
- ORANGE
- OVAL
- PUPA
- RED
- SMALL
- SPOTS
- TREES
- WINGS

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



There are only two ladybugs with four spots. Can you find them?

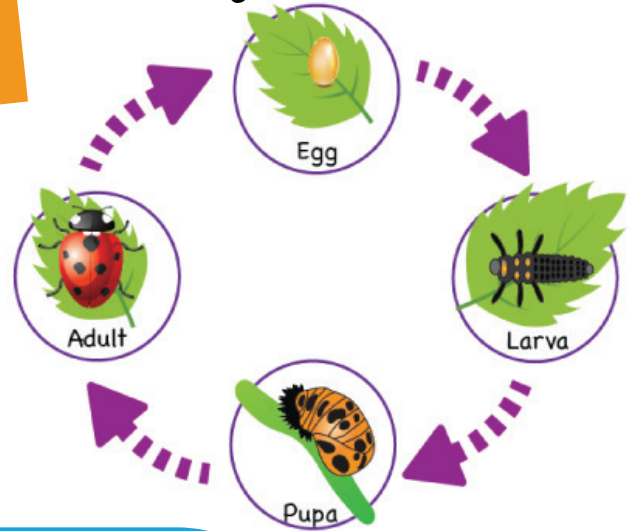
IF YOU CAN READ THIS!

Learn All About LADYBUGS...

The color of a ladybug's spots fade as it gets older. They can live up to two years.

Ladybugs are beetles and considered an insect because they have 6 legs.

Ladybugs pass through four stages in their lives:



Female ladybugs are larger than male ladybugs.






















There are said to be 5,000 species of ladybugs known to be present in the world. They are called "ladybirds" in England.

A ladybug can fly at a speed of 37 mph which is close to the speed of a racehorse. They can flap their wings 85 times per second!



TYPES OF LADYBUGS

 Two-spot Ladybird	 Nine-spotted Lady Beetle	 Twenty-spotted Lady Beetle	 Seven-spot Ladybird	 Fifteen-spotted Lady Beetle	 Yellow-shouldered Ladybird	 Pink Spotted Lady Beetle
 Convergent Lady Beetle	 Fourteen-spotted Ladybug	 Eighteen-spotted Ladybird	 Large Leaf-eating Ladybird	 Ten-spotted Ladybird	 Eyed Ladybug	 Transverse Ladybird
 Thirteen-spot Lady Beetle	 Mealybug Ladybird	 22-spot Ladybird	 Ashy Gray Lady Beetle	 Steelblue Ladybird		

Ladybugs eat aphids, which are insects that suck juices out of plants and crops. Thus, they are considered very helpful to have in your garden!

A ladybug smells with it's feet and antennas.



COOL KIDS CAMPAIGN

WIN A LADYBUG QUILT

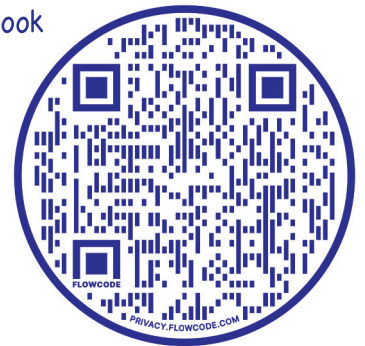


RULES:

1. Complete the form by scanning the QR Code below.
2. Follow Cool Kids Campaign on social media:
@coolkidscampaign via Instagram and
@coolkidsfoundation via Facebook
3. Like the most recent post on each social media page.



This quilt was lovingly hand-made and donated to Cool Kids Campaign by Faithful Circle Quilters.



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WANT AN ARTKIT FOR YOUR CHILD? JUST ASK!

Our Amaeyzing ArtKits are currently being sent to:

- UCSF Benioff Children's Hospital (CA)
- Lucille Packard Children's Hospital Stanford (CA)
- John Muir Health, Walnut Creek Medical Center (CA)
- Kaiser Santa Clara Hospital (CA)
- George Mark Children's House (CA)
- Palm Beach Children's Hospital (FL)
- St. Luke's Children's Hospital (ID)
- Children's Hospital New Orleans (LA)
- Children's of Mississippi (MS)
- Logan Health (MT)
- The Melodies Center at Albany Med (NY)
- El Paso Children's Hospital (TX)

If you are at one of these hospitals, chances are that you have received our Amaeyzing ArtKits. If not, don't worry! Your family can enjoy healing art experiences in the comfort of your own home. Reach out to us www.kidsandart.org/artkit and we'll add you to our monthly Amaeyzing ArtKits @Home subscription program!

DROP-IN ARTROOM

In 2022 we added the Drop-In ArtRoom, a casual, weekly online "drop in" art experience where participants can continue working on their own art project or join a Kids & Art artist for a relaxing, informal hour of art with a like-minded community.

You can sign up for our weekly Drop-in ArtRoom here:
www.kidsandart.org/dropin-artroom



ART IS A "MUST HAVE"

Art is often considered a "nice to have." At Kids & Art, we believe it is a "must have" for quality-of-life care and whole child support. We have seen the impact creativity and artmaking have made on the thousands of families facing cancer with whom we've worked since 2008. If our art programs sound right for your family, please feel free to join us too!

Questions or comments? We would love to hear from you! -
650-877-2750 art@kidsandart.org
Kids & Art is a California 501(c)3. Our tax ID: EIN 27-1415727
<https://www.kidsandart.org>

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**
A LIFEBRIDGE HEALTH CENTER

**CARE
BRAVELY**



Food for Comfort

weis
markets

Christina Pelletier, MS, RDN, LDN
Registered Dietitian at Weis Markets
weisdietitians@weismarkets.com

Meals can be easily forgotten about in times of stress and trauma. Comfort food may be an outlet to help us through these difficult times, however these foods tend to be high in calories and low in a variety of nutrients that are necessary for good health. Keeping a few strategies in mind from the Weis Dietitians, we can get the most nutrition as well as the most satisfaction out of our favorite comfort foods.

GET THE MOST OUT OF COMFORT FOODS

Upgrade to Whole Grain

- For recipes that call for grains such as bread, pasta, or rice, choose the whole grain option. A whole grain pasta in chicken noodle soup will boost fiber, B vitamins, and protein which are all important in a balanced diet.
- Another easy swap is using a whole grain pizza crust with even more bonus nutrients if it is topped with veggies.

Season Smartly

- Make your own flavor pack for tacos or fajitas instead of buying pre-made ones, so they can be customized to your own flavor preferences and use up spices in the pantry.
- Make your own sauces for pizza or pasta. Not only is it a fun activity, but tomato sauces can also easily hide pureed veggies such as carrots, broccoli, or spinach.

Better For You Baking

- Use mashed avocado or apple sauce in place of oil in baked goods to add even more fiber, nutrients, and moisture.
- Bake with veggies such as in Chocolate-Zucchini Muffins or Morning Glory Muffins to pack in the fiber, vitamins, and minerals while still filling that urge to bake.

FITTING IN COMFORT FOODS

Our bodies love routine and consistency, so having regular meals can help reduce some stress. It might be difficult to always make time to eat, however snacks can be kept on hand to fill that gap. These can still be familiar comfort foods that satisfy a craving but also contain important nutrients such as omega-3 fatty acids for brain and heart health, fiber and probiotics for gut health, and even carbohydrates for energy.

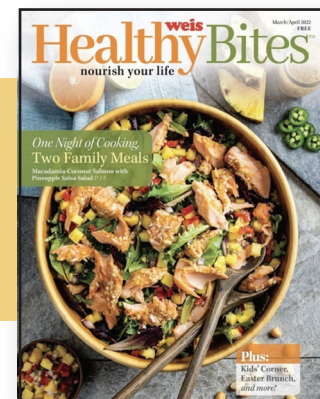
SNACKING

Snacking can be sneaky in stressful situations. Whether we are constantly snacking or not at all, there is a happy medium between the two extremes. Portion controlled snacks that contain at least two food groups are going to be the best option to fill that need. Fiber, protein, and healthy fats keep us satiated for longer with better appetite control and energy.

Comfort foods are not known for being the healthiest, but there are simple swaps that can be made to increase nutrients without compromising on taste. Getting creative with those healthier alternatives can be a fun activity that gets the whole family involved!

Check out our recipe for CHOCOLATE-ZUCCHINI MUFFINS on page 11

Find current and past editions of the Weis HealthyBites Magazine at:
healthybites.weismarkets.com



Chocolate-Zucchini Muffins

INGREDIENTS:

12 Foil Baking Cups
Weis Quality Nonstick Cooking Spray
1 ¼ cups White Whole Wheat Flour
1/3 cup Weis Quality Baking Cocoa
1 tsp Weis Quality Baking Soda
¼ tsp Weis Quality Iodized Salt
1 large Banana, mashed
1 large Weis Quality Egg
1 cup unpacked, shredded Zucchini, squeezed to remove moisture
(about 1 medium zucchini)
½ cup Weis Quality Plain Nonfat Greek Yogurt
1/3 cup Weis Quality 100% Pure Honey
2 Tbsp Weis Quality Unsalted Butter, melted
½ cup Dark Chocolate Chips

DIRECTIONS:

1. Preheat oven to 350 degrees. Line standard 12-cup muffin pan with baking cups; spray cups with cooking spray
2. In medium bowl, whisk flour, cocoa, baking soda and salt. In a large bowl, whisk banana, egg, zucchini, yogurt, honey and melted butter until combined; add flour mixture and stir until just combined. Fold in chocolate chips; divide into prepared cups
3. Bake 24 minutes or until toothpick inserted in center of muffins comes out clean.



—cook at
HOME
with the

WEIS DIETITIANS

Visit the Weis Markets Facebook Events page to learn more and register for our interactive virtual cooking classes for kids and adults! All classes are **FREE** of charge for Weis Market's Preferred Shopper's Club Card holders.

Seeking individualized nutrition counseling? Our Weis Dietitians also offer **FREE** tele-nutrition services! Email weisdietitians@weismarkets.com to schedule an appointment.

weis
Nutrition
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Cool Kids CAMPAIGN®

Send us your stories, art,
poetry, and photos and become
a published writer or artist!



Cami, Relapsed Acute Lymphoblastic Leukemia

Email all submissions to:
janet@coolkidscampaign.org
or mail to:
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is a strong, positive mindset for those living with cancer,
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AFFECTED BY CHILDHOOD CANCER

CONTACT NAME _____

SHIPPING ADDRESS _____

CITY/STATE/ZIP _____

E-MAIL ADDRESS _____ PHONE _____

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

CREDIT CARD # _____

EXP _____ SEC CODE _____ ZIP CODE _____

RETURN THIS FORM TO:

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