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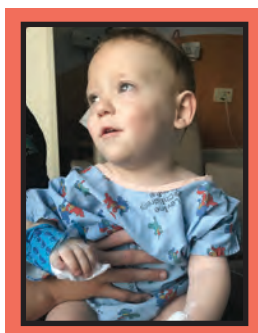
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What Charlie's Journey Taught Us

By Charlie, Ralston, Eva, David, and Kelly Pacetti



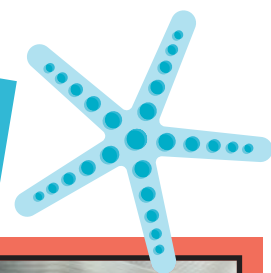
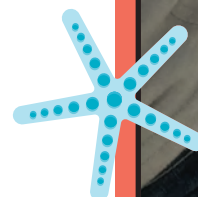
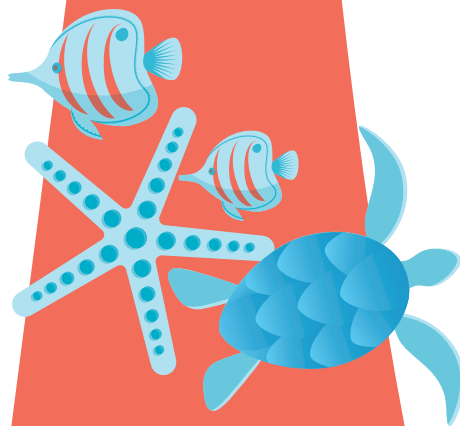
When you first hear your 18-month-old son has an abnormal mass, yet to be identified as cancer, the world stops, and after that it seems like time itself has changed. It speeds up when you are trying to hold him and cuddle. It slows down as you wait for him to

come out of anesthesia, after yet another round of tests. It crawls as you wait for the final diagnosis—hepatoblastoma, with the tumor reaching from the liver up into the heart. Then stops again while he undergoes a 9-hour surgery. It was the beginning of a 7-month journey for our family of five, with Charlie at the center. We were told that if everything went well, we should expect to celebrate Christmas as a family, at home and cancer-free, but “should” leaves a lot of room for error.

The next seven months were filled with ups, downs, and unexpected twists, tears, and lots of love. What surprised us the most during this time was the overwhelming sense of love, support, and prayers we received from our friends, community, strangers, and our cancer team. Support can be a hard thing to accept, but once we embraced that support, we were given the strength to let go and focus on loving Charlie (and siblings). It was like being alone on a boat and looking down and seeing the ocean for the first time. While we thought we were handling it on our own, we realized we were kept afloat by countless others. We were connected to people and organizations through bonds of fear, concern, love, and shared stories that we had never heard but have never since forgotten.

Every night we would look out the window (when able) to find the stars and in the morning to see the sunrise and find hope that each new day God's love would bring our family and Charlie healing, strength, and the ability to in the present moment.

During Charlie's cancer journey he taught us how to live in the moment and to pray deeply. The power of play helps you let go. Totally okay to laugh and have fun even when in the challenging times. Tears can heal the soul and just holding each other is a gift to be cherished.





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ABOUT THIS ISSUE...

Many challenges come along with a cancer diagnosis and navigating them all can seem overwhelming. In this issue, we tackle some problems you might face and offer preventive measures and solutions. You'll meet a Cool Kids family who shares the problems they faced. Adorable Charlie was diagnosed with cancer when he was just 18 months old and his family tells how they discovered support on their journey.

Also in this issue, we'll help you navigate insurance including how to make sure you have the right plan for your family and what to do if your insurance claim is declined. We'll share some kitchen problem solvers. You'll learn what you can create when you are short on time or ingredients so you spend less time over a hot stove. Then we'll share tips for caring for your child – summer is a time for adventure, but accidents can happen and knowing how to prevent infection is critical. And who knows more about solving problems than a Clinical Social Worker? In this issue, we'll meet Tara McAteer who shares more about her life in social work.

We hope you and your family are having a wonderful, problem-free summer. But just in case you need a little help, Cool Kids Campaign is here!

We would like to thank our friends at Triage Cancer, Pacific Medical Training and Weis Markets for sharing their expertise with us in this issue.

Problem Solving in the Kitchen



Emily Bumgarner, M.Ed, RDN, LDN
Registered Dietitian at Weis Markets
weisdietitians@weismarkets.com

Many people are uncertain of how to navigate the kitchen. It just takes a little exploring and learning to feel comfortable. We don't have to be master chefs, but having basic skills is key to making healthy meals. You may even find new foods you enjoy or create a brand-new recipe!

The Weis Dietitians want to make sure everyone feels comfortable in choosing nutritious foods in the grocery store and bringing those foods home to prepare a delicious meal or snack. Let's review some common barriers regarding meal preparation.

What if I don't have enough time?

In today's fast-paced world we are all busy, but we have to eat! It is easy to get food when out and about, but not always the best thing for our health. Try looking at your schedule to see when you have time to prepare meals and choose simple recipes that can be made in 30 minutes or less. Some meals, such as casseroles, can even be made ahead of time and cooked another day. Making time for your health now will benefit you in the long-run.

What if I'm missing an ingredient?

Don't let a missing ingredient stop you from making a recipe. This is a time to get creative in the kitchen! Check your fridge, freezer and cabinets to see what you have on hand that may be a good substitute for

that missing ingredient. Some substitution example include:

- | | | |
|----------------|---|--------------------|
| • bread crumbs | → | round oats |
| • sour cream | → | plain Greek yogurt |
| • ground meat | → | beans |
| • broccoli | → | carrots |

What if I don't like an ingredient or have an allergy or intolerance?

Everyone has food preferences, and we want you to choose food you enjoy, while keeping in mind any allergies or intolerances. Instead of avoiding a recipe because of this, try to find ways to make it work for you. Many times, we can leave out an ingredient or substitute something else to make a dish appealing and safe to eat.

What if I don't know how to perform a technique?

There are endless techniques and terms used in the kitchen, but you can get by in the kitchen by knowing the basics. There are many resources available including some from the Weis Dietitians. Join our virtual cooking classes to get nutrition education as well as some cooking tips and tricks. Check out the Weis Markets YouTube page where we have a Kitchen Tips series consisting of various kitchen techniques in a short video format.

(cont. on next page)

Creamy Chicken & Bell Pepper Rotini

This recipe includes many components that can be prepped ahead of time, allows for substitutions and you can practice various kitchen techniques.

INGREDIENTS

- 2 1/3 cup uncooked Weis Quality whole grain rotini
- 1 tbsp Weis Quality pure olive oil
- 1 lb Weis Quality boneless and skinless chicken breasts, cut into 1/2-inch cubes
- 2 medium orange, red and/or yellow bell peppers, diced
- 1/2 small white onion, diced
- 2 cup no salt added pasta sauce
- 1/4 cup Weis Quality Neufchâtel cheese, softened
- 1/3 cup Weis Signature Collection shaved parmesan cheese
- 3 tbsp coarsely chopped fresh basil

DIRECTIONS

- Prepare pasta as label directs; reserve 1 cup cooking water and drain.
- In a large nonstick skillet, heat oil over high heat. Add chicken, peppers and onion; cook 6 minutes or until chicken is browned. Add pasta sauce, Neufchâtel cheese and cooking water; cook 6 minutes or until Neufchâtel cheese melts and internal temperature of chicken reaches 165°, stirring constantly. Stir in pasta; cook 1 minute or until heated through, stirring frequently. Makes about 8 cups.
- Serve pasta garnished with parmesan cheese and basil.



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Weis HealthyBites Magazine at:
healthybites.weismarkets.com



—cook at
HOME
with the

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Seeking individualized nutrition counseling? Our Weis Dietitians also offer **FREE** tele-nutrition services!
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weis
Nutrition
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Getting to Know A Clinical Social Worker



Interview with Tara McAteer, Clinical Social Worker by Madison McVay-Edwards, 2021 Cool Kids Clubhouse Intern

Clinical Social Worker, Tara McAteer is from Danville, New Jersey. She attended Dickinson College in Pennsylvania and then transferred to Lehigh University. Focusing her studies in Social Psychology, she completed her undergraduate program and attended graduate school at Columbia University in New York. Since 2019, Tara has been a Pediatric Bone Marrow Transplant Social Worker at Levine Children's Hospital working in Cellular Therapy (Bone Marrow Transplant Team).

Tara became involved in pediatric oncology because she struggled with immune health which resulted in her being a sickly child. She understood how it felt to have many doctors appointments as well as missed days in school. After graduate school, Tara participated in a number of internships that led her to social work. She wanted to provide families with access to healthcare, as well as make sure that they experience a safe and trusting environment.

Here is a recap of the interview with Tara:

Q: How does your role support pediatric children and families?

A: Every situation is unique in its own way and that's why I love my job. Being able to help families and support them when things get tough is my job. The way we support patients depends on their treatment journey, whether it be financial support, family support, or emotional support - anything that is needed. The patients and families are our priority.

Q: What are some of the most rewarding aspects of your role?

A: The most rewarding aspect of my job would have to be when you see patients off of treatment and they are doing better than before. It has caused me to tear up just thinking of so many smiling faces. It also makes me think of all of their hard won accomplishments. Seeing so many success stories makes the job gratifying. Situations that seem impossible can turn into a success story.

Q: What are some of the hardest aspects of your job?

A: The hardest aspect of my job would have to be that every family should have my attention, but I can only be in one place at a time. But at the end of the day, all of our families are prioritized and they receive unconditional support. Another challenge is addressing psychosocial stressors such as guardianship, homelessness, etc..

Q: How do you manage stress and stay focused on the families?

A: I always remember that families are a priority - we want the families to know that our hospital family is also their family. Self-care is a challenge, but I know that having personal headspace is needed to manage stress. Also, being able to see patients and their families brightens my day and helps me to remain focused while also managing self-care.

Q: What would you like to say to patients and/or families currently going through treatment?

A: "You are gonna get through this". When it comes to social work in the hospital, let your clinical social worker provide the help that you need. They work for a team that cares for you as the patient and family.

Q: What do you wish others could know or understand (either about your role, the families, or the kids)?

A: We would like for people to understand that social work is a wide variety, and that we have good reasons for the questions we ask. I'd like people to understand the importance of the work.

SOME FUN QUESTIONS:

Q: What's your favorite holiday and why?

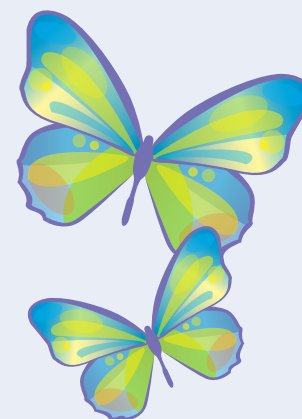
A: Christmas. Ever since I was a few years old, my mom taught my sister and I that it was important to give family and friends a gift. We always put a lot of time and effort into the gifts we made or purchased with the money we saved throughout the year. I loved seeing my cousins and grandparents on Xmas eve, and always got new pajamas from Santa to wear in the car on the way home.

Q: What's your favorite food?

A: Mexican

Q: Do you have any pets?

A: Piper is my 2.5 yo golden poodle



PUZZLES AND GAMES



SUMMER Fun



WORD SEARCH

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



BEACH
CAMPOUT
COOKOUT
FIREWORKS
FLIP FLOPS
LAZY

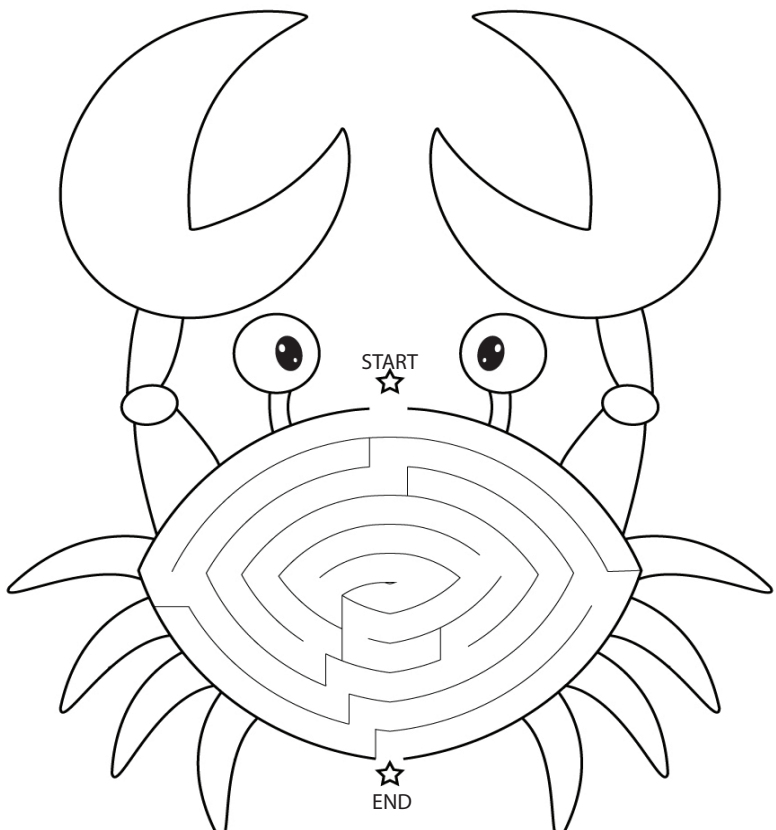
LEMONADE
POOL PARTY
POPSICLES
SANDCASTLE
SMORES
STARGAZING

SUMMER
SUNGLASSES
SUNSCREEN
SUNSHINE
SURF
SWIM


 TROPICAL
VACATION
WATERMELON
WATER PARK



Crab Maze!



Find your way through the crab shell from START to END.
Then color the crab red!

KID SNAOK

Fill in the grids so that each column, row, and box contains each of the numbers from 1 to 4.

4			1
1		3	
	4		3
3			2

1			4
	4	3	
	2	1	
3			2



ANSWERS

1	4	2	3
3	2	4	1
4	1	3	2
2	3	1	4

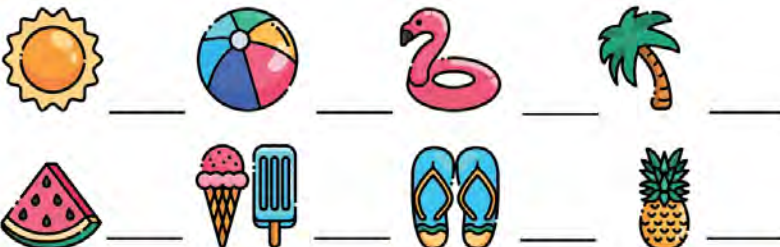
3	1	4	2
4	2	1	3
1	2	3	4
2	3	4	1

Brain in the Awards



I SPY SUMMER CHALLENGES

Count how many of each picture you find.
Write your answer on the lines below each puzzle.





Let the Olympic Games Begin!



Get the scoop on the history of the Olympics:

The first known Olympics were held about 3,000 years ago at Olympia, in southern Greece. Originally, the games were part of a religious festival to honor Zeus. He was known as the leader of the Greek gods who lived on Mount Olympus, the highest mountain in Greece. The competitive games were held every 4 years until they were banned by an emperor in the 4th century.

The Olympics started back up in 1896 thanks to a French educator and historian, Pierre de Coubertin. Pierre loved sports and felt that the world's countries would have more of an opportunity for peace if they gathered together to play sports. He designed the five color rings that are used to represent the Olympic Games today. The rings stand for North and South America, Africa, Asia, Europe, and Australia. At the beginning of the games a flame is lit in Olympia and is passed from torch to torch until the location of the games is reached. To accomplish this, the Olympic torch has had to travel by boat, airplane, horseback, camel, via radio signal, underwater, and even in a canoe!

Today thousands of athletes from hundreds of countries all over the world compete for the gold (or silver or bronze) in the summer and winter events. Check out the current 2021 Summer Olympics in Japan to begin July 23rd!

Did you know...



Gold medals were only made of pure gold up to 1912. These days, they are made of silver and have a gold plating.



The Beijing Olympics, 2008, began at exactly 8:08:08 PM on 8/8/08 because the number 8 is considered lucky in China.



The youngest medalist ever in an individual event was Inge Sorensen from Denmark. She won a bronze medal in the 200-meter breaststroke in 1936. She was only 12.



In the 1912 Olympics there was a wrestling match that lasted 11 hours!



At the opening ceremony, the host team always walks last in the Parade of Nations. The first country is always Greece, where the Olympics originated. The parade was first held in the 1908 Games in London.



Romania's Nadia Comaneci was the first gymnast to score a perfect 10. She was 14 at the time.



Michael Phelps holds the record of winning the most Olympic medals. He has won 28 medals: 23 Gold, 3 Silver and 2 Bronze.



Artists once competed in the Olympics. From 1912-1948, medals were up for grabs in disciplines like painting, sculpting, writing, and music.



At least one of the Olympic Rings' colors appears in every national flag.



During the 1936 Berlin Games, two Japanese pole-vaulters tied for second place. Instead of competing again, they cut the silver and bronze medals in half and fused the two different halves together so that each of them had a half-silver and half-bronze medal.

COOL COLOR ME



Preventing Infection in Children With Cancer

This article was provided by Pacific Medical Training. For more information, visit their website support@pacificmedicaltraining.com and for this specific article, visit <https://pacificmedicaltraining.com/first-aid-for-people-with-cancer.html>

WHAT YOU SHOULD KNOW

It is normal for parents who are caring for a child with cancer to feel scared and nervous. But with planning, you can help your child through his or her treatment, and watch your child return to a normal life. Knowing the signs and symptoms of an infection and knowing the steps you can take to prevent infections may help make this challenging time easier to get through. This Health Tip Sheet will give you some important information that will help you take care of your child.

CHEMOTHERAPY AND INFECTION

Chemotherapy is the most commonly used treatment for childhood cancers. These powerful cancer-fighting drugs work by killing the fastest-growing cells in the body—both good and bad. That means that along with killing cancer cells, healthy white blood cells called neutrophils often get destroyed too. When the number of white blood cells is reduced, a condition called neutropenia occurs and can increase your child's risk for getting an infection. This is a common and serious side effect of cancer treatment.

Since the length of time it takes your child's blood counts to drop depends on the dose and type of drug used, you should talk to your child's doctor about when they are likely to be at an increased risk for infection.

When caring for your child, it is important to do the following:

- Take your child's temperature if he or she feels warm, has the chills, or does not look or feel well.
- Treat a fever as a medical emergency. A fever may be the only sign of infection your child will experience. Call his or her doctor immediately if they develop a fever, even in the middle of the night. Do not wait for the office or clinic to open.
- Know the other signs or symptoms of infection and call your child's doctor immediately if he or she is experiencing any of these signs or symptoms.
- Take steps to lower your child's chances of getting an infection.

OTHER SIGNS AND SYMPTOMS OF INFECTION

While monitoring your child for a fever is important, there are several other signs or symptoms you should know about that may mean your child has an infection, including the following:

- Chills and sweats
- Shortness of breath
- Stiff neck
- Runny or stuffy nose
- Change in cough or a new cough
- Sore throat
- Earache
- Headache

Additional signs and symptoms that may mean your child has an infection include:

- Burning or pain when using the bathroom
- Increased urination
- Stomach pain
- Loose bowels/diarrhea
- Vomiting
- Sores or pain around the rectum
- Changes in skin (e.g., blisters, rash, skin sores); check your child's skin and mouth daily
- Redness, swelling, pain, or pus at the site of a surgical wound or central venous access device (central line or port)
- New onset of pain
- Change in mental status (e.g., confusion, depression)

Children who receive chemotherapy can be at high risk for getting a serious infection. If this happens and your child does not receive medical care right away, your child could get very sick and may even be at risk for dying. If any of the above signs occur, contact your child's doctor or nurse immediately. Do not wait until their office or clinic is open.

PREVENTING INFECTIONS

Keep in mind that playing with friends, attending school, and other daily activities, such as sports are a big part of your child's life. How soon your child should resume these activities after chemotherapy should be discussed with your child's doctor.

There are some steps you should take to lower your child's risk for picking up an infection:

- Encourage your child to wash his/her hands often to prevent the spread of germs from one person to another. You and other family members should also wash your hands regularly. Hand washing is the most important way to prevent infection. If soap and water are not available, you may use hand sanitizer.
- Encourage your child not to use cups, eating utensils, or toothbrushes used by others.
- Encourage proper mouth care. Have your child brush his or her teeth with a soft toothbrush after waking up in the morning, before going to bed at night, and after eating meals.
- Help your child avoid contact with other children and adults who have infections such as colds, diarrhea, flu, chicken pox, or shingles.
- Your child should not receive any live virus vaccine, such as oral polio or the mumps, measles, rubella vaccine (MMR), or varicella vaccine (the chicken pox vaccine) while on treatment. Live vaccines can cause illness, as your child's body cannot get rid of the viruses. Your child's healthcare provider should advise about vaccinations and what is safe to receive. To be safe, talk to your child's healthcare provider about vaccinations that your other children or family members should receive.
- It is important that your child receives an annual flu vaccine, as should his or her close contacts, including the other members of your immediate family. Be sure to ask for the seasonal flu shot, not the nasal spray flu vaccine. The flu shot is made up of inactivated viruses (killed) and the nasal spray vaccines are made up of live viruses. The flu shot is safer for those with a weakened immune system.
- Talk to your child's doctor before taking them to the dentist.

MORE TIPS ON PREVENTING INFECTIONS

Here are some additional steps you should take to lower your child's risk for picking up an infection:

- Discuss your child's condition, treatment and infection risk with school personnel.
- Discuss international travel plans with your child's doctor.
- Check with your doctor before letting your child use a swimming pool or hot tub.
- Try to stop your child from playing with toys that have come into contact with other children. Regularly wash soft toys and security blankets in the washing machine, and wipe down other toys to keep them clean.
- Do not feed your child raw or undercooked meat or eggs.
- As a caregiver, you should avoid artificial nails.



Making the Most of Health Insurance

By Hope Medina – Triage Cancer

When your child is diagnosed with cancer, the last thing you probably want to think about are the legal and practical issues that arise. Will your child be able to get the treatment they need? How will you pay for that treatment? How will the diagnosis and treatment impact your job and family's finances? Will your child be able to continue at school? The answers to all of these questions are often rooted in the law. That is why Triage Cancer offers free events, materials, and resources on the practical and legal issues that arise after a cancer diagnosis to individuals who are diagnosed, and their caregivers.

One of the major contributors to the financial burden of a cancer diagnosis is related to health insurance. The first step is to make sure your family members have the right plan for them. That may mean that all family members are under the same plan, or it may mean that family members are split up. For example, if your child's doctors are out-of-network for the plan you have through your employer, it may make sense to see if your child can access their own plan on the Health Insurance Marketplace.

The Marketplace, created by the Patient Protection and Affordable Care Act (aka ACA or Obamacare), allows you to see your health insurance options from private insurance companies. Almost an insurance shopping mall, the marketplace offers plans with standardized cost-shares, a cap on out-of-pocket maximums, and financial assistance. This helps you know how much you will pay for your medical care before you buy a plan; in 2021, Marketplace plans cannot have an out-of-pocket maximum more than \$8,550 for an individual and \$17,100 for a family. Depending on your household size and income, you may qualify for "premium tax credits," which lower your monthly premium based on the plan you chose. And, "cost-sharing subsidies" can lower co-payment amounts, deductibles, and co-insurance amounts. Even if you have looked into the Marketplaces in the past, it may be worth checking again because there is additional financial assistance available for 2021 and

2022 plan years, through the American Rescue Plan. For more information about Marketplace plans, read Triage Cancer's Quick Guide to Health Insurance Marketplaces, <https://triagecancer.org/quickguide-marketplaces>.

The second step, is ensuring you are making the most of the health insurance policy you have. As you and your family grapple with a cancer diagnosis, your insurance company may say "no" to a treatment you know is necessary, whether for an imaging scan, prescription drug, treatment, procedure, or genetic test. Most people take "no" for an answer. But, if you don't accept the denial, you could join 60% of people who appeal their claim denials and win!

You can file an appeal before or after care. Regardless of when the care was received, there are three steps critical to filing an appeal:

1. Step 1: Contact the Insurance Company. Ask for a detailed explanation of the denial and the company's internal appeals process. Keep track of all communications with the insurance company, including the names and contact information of representatives you spoke with. © Triage Cancer 2021
2. Step 2: Understand the Denial. There are many reasons why insurance companies may deny your claim, ranging from mistakes to pre-authorization. Finding out why the claim was denied helps you overturn the denial.
3. Step 3: Gather Evidence. Gather evidence including letters from providers, relevant medical studies, and personal letters explaining your situation.

(continued on next page)

Cool Kids CAMPAIGN®

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poetry, and photos and become
a published writer or artist!



Cami, Relapsed Acute Lymphoblastic Leukemia

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or mail to:

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CREDIT CARD # _____

EXP _____ SEC CODE _____ ZIP CODE _____

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