

CONNECTING PEDIATRIC ONCOLOGY PATIENTS THROUGHOUT THE NATION

By: Adam Sparks

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People go through challenges every day. Some bigger than others. I would like to share my challenges with you, to help you and others understand how they helped me learn how to help others and how Cool Kids helps me do that.

My name is Adam Sparks. On February 14th, 2007 I was diagnosed with Stage IV Neuroblastoma. I went through a lot of treatment, got clean, but then relapsed when I was 5 years old. I do not remember every detail as I was pretty young, so I have my mom helping me write this. She has more of the details to help me back up the feelings I had while going through everything.

When you get sick it doesn't matter how old you are- it will change your life. It can come out of nowhere. Who knew a bump that my mom saw on the side of my head could have put us on such a rough path. We had a lot of treatment and travel ahead of us that even we did not know at the time.

I started my chemo treatments at home in Charlotte, then Presbyterian-Blume. We went to NYC to MSKCC for surgery to remove my main tumor. Then we did my stem cell transplant and radiation at Duke Hospital. I remember it was long. Then I went back to NYC for antibody treatments. I missed my family. I was tired of travelling. I was finally in remission and all was looking well for my family. I was in preschool, playing soccer and everything was good.

In March of 2010, they found another tumor in my leg. Relapsed Neuroblastoma at that time had very low chances of survival, so my family was very worried. But they stayed positive so I could stay positive. I went back into treatment- Charlotte and NYC. I was clean again, but still in treatment. There were not a lot of options for us to help prevent it from coming back so we moved my treatment plan from MSKCC to CHOP in Philadelphia.

I stayed on an experimental low dose chemo through CHOP for 3 years, worked with their endocrinology group for my growth issues, and I am presently still going up there to meet with the long term survival team. So, long story short, we dealt with a lot of travel, a lot of time away from family, a lot of time away from school and friends.

So, now that my mom has filled in a lot of the basics, here is what I remember and these are the parts that made me the strongest. There are many things that can change your life when you are sick- the people you meet, the people you lose, and the things you see and hear. It is a lot to take in. And sometimes when you are going through it, you do not even realize how much these things affect you until later. They can have so much of an impact on your life and you don't even realize it. You meet people you love, nurses and doctors and friends. You can lose some of those friends and that is very hard, but I learned a lot. I learned that my past will not hold me back.



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### ABOUT THIS ISSUE...

Our Winter, 2021 edition focuses on total wellbeing – physical, social and emotional. Now more than ever taking care of your entire self is critical.

We are excited to partner with the dietitians at Weis Markets this year to provide you with nutrition information and recipes that can help you maintain a healthy body. At the same time, these recipes are easy to execute and, of course, delicious. We are so excited to be able to share the expertise of these wonderful dietitians. And if you want more, go to our YouTube channel at https://tinyurl.com/CoolKidsNutritionSeries where we partner with Weis Markets to provide nutrition information and recipes every other week.

To help overcome the social isolation you might be feeling, we are sharing information on the CoHeals app. This is a mobile app created by the mom of a child with cancer and it helps parents dealing with childhood cancer to personally connect. Imagine being able to use your phone to find another parent dealing with the same diagnosis – you really are not alone in your journey.

The Johns Hopkins International Arts & Mind Lab has shared information on how getting out in nature can improve your emotional wellness. And if you can't go out, there are even tips for bringing nature indoors. And if you need even more inspiration, take in the wise words of our own Cool Kid Adam Sparks who shares thoughts on his cancer journey.

Taking the time to care for yourself means you can be better able to care for your child and others around you. We hope these articles help you do just that.

In Our Next Edition - Look for our Spring Connection in May when our focus will be on teens.

### ~ continued on from the cover ~

Things in my life will be different because of what I went through. I missed some school. I had to repeat a grade. I missed out on a lot of socializing when I was young. I missed out on sports. But my life did not stop because of a few setbacks. I have made a promise to myself that I will not be limited by what I went through and what I missed for my future. I am working on the side effects that have been a result of the treatments and I am moving past them. I know in my heart that anyone can do something if they try.

This all comes down to why I love Cool Kids and why I volunteer. I went through all of it without this great place where I could go and be with kids just like me. I am 16 years old and I still have people looking at me a little funny when they find out I had cancer. Sometimes, you just need to be with people who get it. And you can completely be yourself, with all of your issues. Because everyone else in the room gets it. That is what I feel Cool Kids is all about.

I love volunteering with this group so much. The kids come in smiling and they have so much fun. Nothing can make me happier. Getting sick is hard on all of these kids, so seeing them having fun and enjoying their time is very important to me. I love sharing that with them.

Life is what you make of it. It's not about what you can't do, it's about what you can do. How hard are you gonna work to get what you want? I push my goals every day because if I have learned anything from my journey, it is that I need to defy the odds and make my own path and persevere through life. This is what I hope all of these incredible kids do as well.

### Adam Sparks

Volunteer - Cool Kids Clubhouse in Honor of Dan Jansen Cool Kids Campaign Teen Advisory Board Member



Adam & Dan Jansen



# Heart Health Month

## Taylor Simpson, MS, RDN, LDN

Registered Dietitian at Weis Markets tbsimpson@weismarkets.com

February is Heart Health Month which is a time to bring awareness about foods and eating habits that can promote a healthy heart. Below are several heart-smart foods and tips to incorporate them into your meals. Though we highlight a few foods below, keep in mind that a heart-smart diet includes a variety of fruits, vegetables, whole grains, nuts, beans, unsaturated fats, lean proteins, and seafood.

### **AVOCADOS**

Did you know that avocados are one of the only fruits that provide heart-healthy fats? They also provide fiber, vitamins, and minerals. When choosing a ripe avocado, apply gentle pressure with your finger to the area near the stem. If there is a slight give, the avocado is ripe and ready to use in your favorite recipe. Try incorporating diced avocado into salads and grain bowls, or mash avocado for some guacamole and then add to tacos or burritos. You can also toast some whole grain bread and top it with sliced or mashed avocado for avocado toast. Get creative and top your avocado toast with fresh herbs and spices, everything bagel seasoning, or check out my favorite recipe below!

### **NUTS**

Nuts, or all varieties, including almonds, pistachios, and walnuts are chock full of unsaturated fats, fiber and plant-protein. They make for a nutritious and portable snack too! When shopping, choose low sodium or unsalted nuts when available and avoid those that are glazed or otherwise high in sugar. Nuts are delicious on their own and also lend a satisfying crunch as a topping for salads, yogurt, and oatmeal.

### **FISH**

The American Heart Association recommends two servings (about 4 ounces each) of fish per week. Salmon, lake trout, fresh albacore or canned light tuna, cod, haddock, catfish and pollock are some great options. Try cod in fish tacos, add canned light tuna to a salad or wrap, or bake salmon in the oven with veggies for a one pan meal. Check out one of my favorite one pan recipes for fish on the next page.

### **OATS**

Oats provide a type of soluble fiber that may help lower your "bad" (LDL) cholesterol which can promote heart health. Enjoy oats traditionally prepared and served hot or try them in overnight oats. Simply combine ½ cup of oats with ½ cup of the milk of your choice with fruit, nuts, cinnamon, and optional sweetener. Refrigerate 8 hours to overnight for a creamy and delicious breakfast the next day!

### **OMEGA-3'S**

Omega-3 fats are a type of unsaturated fats that may help reduce inflammation in the body and, in turn, benefit your heart. Walnuts provide more plant-based omega-3s than any other nut. Other plant sources of omega-3s include flax and chia seeds and canola oil. Try incorporating ground flaxseed or chia seeds into overnight oats, yogurt or baked goods to give them a boost. Fatty fish such as salmon and tuna also provide omega-3s and are a more familiar source of this good fat. If you have difficulty including the recommended 2 servings of fish in your diet per week, strive to include a variety of the plant sources instead.

# Heart Smart Recipes

### PROTEIN POWERED AVOCADO TOAST Serves 4

### **INGREDIENTS:**

- 1 Avocado From Mexico
- 1 cup Weis Quality Cannellini Beans, drained and rinsed
- 1 tbsp lemon juice
- 1 tbsp Weis Quality Stone Ground Dijon Mustard Salt and pepper to taste
- 4 slices of whole grain bread, toasted

### **DIRECTIONS:**

- 1. In a medium bowl, mash together avocado, beans, lemon juice, mustard, salt and pepper.
- 2. Spread avocado mash on toast and garnish with basil.





### ROASTED ASIAN-GLAZED SALMON & VEGGIES

Prep: 15 minutes Roast: 25 minutes · Serves: 4

### **INGREDIENTS:**

1 (8-ounce) head broccoli, cut into 2 inch pieces

6 ounces shiitake mushrooms, stems removed

2 medium carrots, peeled and cut into 1 inch pieces

1 small red onion, cut into 1/2 inch wedges

2 cups sugar snap peas

1 tbsp Weis Quality Pure Olive Oil

1/4 tsp Weis Quality Iodized Salt, divided

1/2 tsp Weis Quality Ground Black Pepper, divided

1 garlic clove, minced

2 tbsp hoisin sauce

2 tsp chili garlic sauce

1-1/4 pounds fresh salmon fillet

### **DIRECTIONS:**

- 1. Preheat oven to 425°. Line rimmed baking sheet with parchment paper.
- 2. In a large bowl, toss broccoli, mushrooms, carrots, onion, snap peas, oil, 1/8 teaspoon salt and 1/4 teaspoon pepper; spread in a single layer on prepared baking sheet. Roast vegetables 15 minutes.
- 3. In a small bowl, stir garlic, hoisin, chili garlic sauce, and remaining 1/8 teaspoon salt and 1/4 teaspoon pepper. Move vegetables to one side of baking sheet; place salmon, skin side down, on opposite side of baking sheet. Evenly spread hoisin mixture over salmon.
- 4. Roast salmon and vegetables 10 minutes longer or until internal temperature of salmon reaches 145°, it flakes easily with a fork and vegetables are crisp-tender. **Healthÿ**Bites

Approximate nutritional values per serving: 353 Calories, 14g Fat (2g Saturated), 90mg Cholesterol, 432mg Sodium, 20g Carbohydrates, 5g Fiber, 8g Sugars, 3g Added Sugars, 36g Protein Recipe from the Sept/Oct Edition of the Weis HealthyBites Magazine

Find the current and past editions of the Weis Healthy Bites Magazine at healthybites. weismarkets.com



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.







DIRECTIONS: Find and circle the vocabulary words in the grid. Look for them in all directions including backwards and diagonally.

**It's Snow Time** 

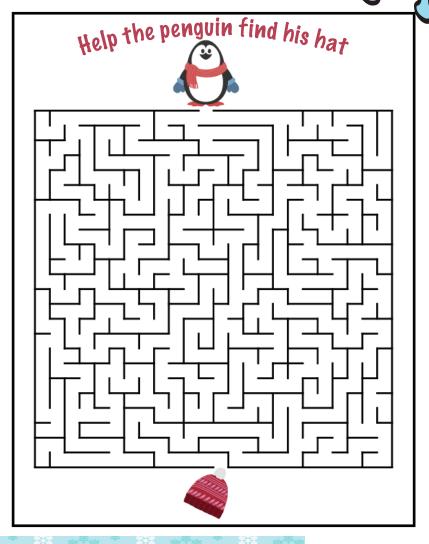
Word Search

BLIZZARD

COLD DRIFT FLURRY FROSTY FROZEN ICE CRYSTAL ICE SKATE **ICEBERG** 



ICICLE SLIPPERY IGLOO SNOW FORT MELT SNOWBALL PACK SNOWBANK PLOW SNOWBOARD POWDER SNOWMAN SHOVEL STICKY SKI SUB-ZERO WHITE SLED



### WINTER SUPOKU

To complete this sudoku puzzle, fill in the grid so that each row, column, and mini-grid contains the letters from the word SNOW.

		0	
0			N
	W		
S	0		W

### WINTER SUPOKU

To complete this sudoku puzzle, fill in the grid so that each row, column, and mini-grid contains the letters from the word FROZEN.

		0			Z
			F	E	
0					E
	R		0		
			Z	F	
Z		F		0	R

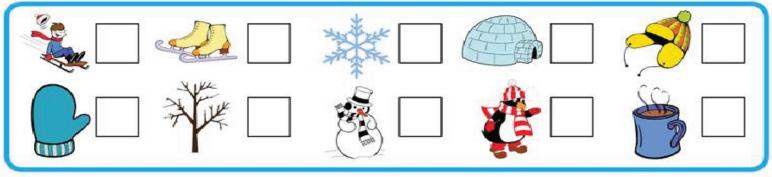
**ANSWERS:** 

M	N	0	S
0	S	M	Ν
Ν	M	s	0
s	0	Ν	M

Я	0	3		Ν	Z
Ν	4	Z	Я	0	3
Н	Z	0	3	Я	Ν
3	Я	Ν	Z	Н	0
0	3	4	Ν	Z	Я
Z	Ν	Я	0	3	4

# BIRTHI THE STERRISH

ISPY How many can you find?





Did you know...

Applesauce was the first food eaten in space by astronauts.

Cans of diet soda will float in water but regular soda cans will sink.

Snails take the longest naps. They can sleep up to 3 years!



Giant Pandas eat

approximately 28

pounds of bamboo a

day - that's over 5

tons per year!

A typical cough is 60 mph while a sneeze is often faster than 100 mph.



Hippopotamus milk is pink.



Kangaroos

can not

walk backwards.



Cows can walk up stairs but not down them.

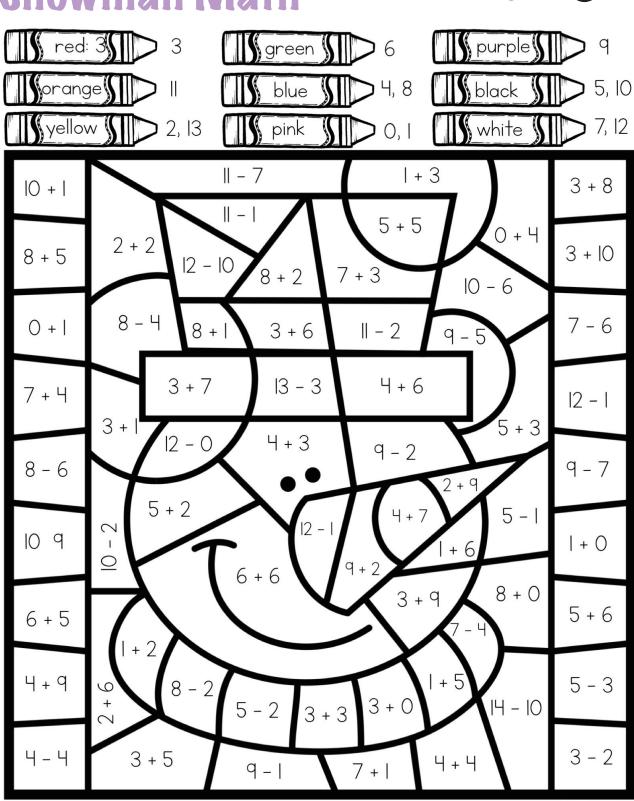


Your fingernails grow faster when you are cold.

All babies are born with blue eyes.

Cats are not able to taste anything that is sweet.

# Snowman Math



# New App Connects Pediatric Cancer Families - Tatum Fettig's Story -

CoHeals

Sweet Tea

- by Tatum Fetting with Renee Wooding

Social isolation is not only a problem for children with cancer, it is a big problem for their parents, as well. Sometimes you really need to talk to someone who has traveled this path before, but finding these parents can be difficult. This is the story of how Tatum Fettig faced this problem and has created a mobile app to help parents of children with cancer connect. Thanks to her efforts, you can now more easily connect to other parents.

### TATUM'S STORY

Mother to two beautiful children, Judd (5 years old) and Teagan (3 years old), Tatum and her husband Jeff's lives were forever altered in December 2016 when Teagan "Sweet Tea" was diagnosed with medulloblastoma (a malignant brain tumor). Thrust into the difficult world of pediatric cancer, Tatum figured out a way to "give purpose to the pain". During her daughter's diagnosis and entire treatment, Tatum and Jeff were at the hospital for days, weeks, and months on end. While they received an immense amount of support from their community of family, friends, and skilled and compassionate medical team, they didn't know any other families going through what they were: constantly yearning for another day with their child, praying at night they would get to witness their child grow up, experiencing the full onslaught of emotions of grieving the loss of life they had before and knowing they will never return to that life again, and reverently holding on to the power of hope and the courage to fight with every fabric of their being.

Because of HIPPA regulations and patient confidentiality issues, the doctors and staff legally could not put them in touch with other parents who were also going through their ordeal. When Tatum met two mothers (by happenstance in the pediatric oncology hallways) she knew she was not alone in her journey. She knew that others knew her pain, that others could relate to her fight, that others were finding support and staying resilient. These powerful connections helped her when she was down and reduced her suffering. When she connected with someone else in her shoes it gave her hope.

It was then that Tatum began her mission of helping parents of pediatric cancer patients connect.

### **HER PATH FORWARD**

Tatum had a vision to create a nonprofit, healthcare mobile app and she has made that dream a reality the CoHeals App is now live! The app specifically addresses quality of life and psychosocial issues (e.g., experiential isolation and loneliness) as it serves to decrease suffering and increase hope. The goal is to connect parents to ensure that parents with children with cancer as well as bereaved families can remain functional, intact, and connected with other parents who are going through what they are. parents are healthy and supported,



this often can allow them to be more available to their children, which helps promote healing.

### WHAT THE APP DOES

The CoHeals App allows parents of Pediatric Oncology patients:

- Find Others Who Get It-Specific Search Filters: Finding someone who understands even a small piece of your journey with your child with cancer can help.
- Meet in Person: Medical settings can be isolating and unpredictable. Post treatment can as well. Using our geolocator, you can find parents and caregivers who are nearby you in the moment.
- Avoid wasted time. You don't have energy to waste. Learn about others before you reach out by reading our caregiver and child profiles on our mobile app.
- Feel secure the CoHeals app is moderated by clinical social workers CoHeals partners with the Children's Brain Tumor Foundation whose clinical Social Workers help assist with the moderation of the app community.

### FEATURES OF OUR APP INCLUDE:

- Live newsfeed
- Find-allows you to put in search criteria to find specific parents with children with similarities (cancer type, treatment phase, hospital location, diagnosis location, child's age, child's sex, child's gender)
- Groups-by cancer type or varying needs
- Events-where you can list events
- Invite Friends-text or email other parents in ped onc community
- Conversation-chat

### HOW TO ACCESS THE APP

Users can sign up through the app store link or the link for the CoHeals app in the google play store. The links can also be found on the homepage of the CoHeals website.









## Why a Dose of Nature Is Essential to Your Mental Health

This article was published by The International Arts + Mind Lab (IAM Lab) which is a multidisciplinary research-to-practice initiative from the Pedersen Brain Science Institute at Johns Hopkins University that is accelerating the field of neuroaesthetics.

When was the last time you went out and soaked up some nature? Even in pre-pandemic times, most American adults spent 93% of their time indoors. Now, with social distancing requirements in place, the time we spend at home and inside has only increased.

During this stressful time, our connection to nature is more important than ever for maintaining our mental health and wellbeing. As the neurologist Oliver Sacks put it, "I cannot say exactly how nature exerts its calming and organizing effects on our brains, but I have seen in my patients the restorative and healing powers of nature and gardens." The research confirms what human beings have intuited for millennia: Mother Nature knows best when it comes to our health.

### THE GREAT OUTDOORS ARE GOOD FOR YOU-NATURALLY

Nature experiences are associated with many benefits like better moods, less anxiety and obsessive thinking, and positive social interactions with neighbors. In neighborhoods with more green spaces, research has found better self-reported wellbeing and overall happiness within the community, as well as lower odds for developing a litany of physical ailments, including cardiovascular disease, diabetes and obesity, as well as death. For patients with physical illnesses, nature exposure may be a cost-effective intervention for improving their self-reported mental health.

What is nature's secret? It may come down to nature's ability to improve our sleep quality and lower stress. These improvements to our underlying biology may account for the growing evidence that nature experiences can prevent the development of mental illnesses, such as depression, anxiety disorders, and attention deficit and hyperactivity disorder. For children, the presence of nature in their neighborhoods could be essential to their mental health. Growing up around green space is associated with a lower risk of developing almost all major types of psychiatric disorders including depression, anxiety disorders, substance abuse, eating disorders, and schizophrenia.

### **GETTING YOUR REGULAR DOSE OF GREEN**

The "dose" of nature matters: the more green you get, the better your health outcomes. One study found that visiting outdoor green spaces for at least 30 minutes per week was associated with reduced rates of depression and high blood pressure.

A walk through nature is restorative, particularly during stressful times. In one study of college students, researchers found that walking through nature, viewing nature and walking on a treadmill all reduced cortisol. But walking in nature was the most potent stress reliever of the three approaches, reducing students' cortisol by 25% during a particularly stressful period—exam time. The richness of nature you encounter on that therapeutic walk outdoors also matters. Greater diversity of plant life and bird species has been tied to a lower prevalence of depression, anxiety, and stress.

### **ENJOYING NATURE FROM THE COMFORT OF HOME**

The pandemic has made it more challenging to get outside. Many of us are isolating at home to reduce the risk for ourselves and loved ones, particularly-more vulnerable seniors and immunocompromised individuals.. Some states

are still enforcing orders to stay home—or close to it—although they permit exercise outdoors with the appropriate social distancing. (To see a summary of the guidance in your state, check your state government's health website.) In addition, the majority of all people on earth now live in cities, which may make it more challenging, and even more critical, to access green spaces that allow for adequate social distancing. Fortunately, you can still reap nature's benefits from home.

Gardening is one way of going green closer to home. One study reports that visiting a private garden 4-5 times a week reduced the odds of depression, improved a sense of social connection, and even levels of physical activity. Another study found that gardening for 30 minutes reduces stress, cortisol levels, and improves mood. Extended exposure to gardening has been successfully incorporated in a rehabilitation program for patients with severe stress and depression in Sweden, leading to a faster return to work.

If you don't have space for a garden, you can also bring nature and its benefits directly into your home. Indoor nature exposure, such as plants, windows with a view of nature, or art depicting nature, has been found to improve mood, restore attention, decrease stress, and diminish fatigue. Direct sunlight exposure in the workplace (which, for many of us, is now our homes) has been found to improve job satisfaction and decrease depressed mood and anxiety. Adding reminders of nature like potted plants, landscape paintings, or nature screensaver to your living space could be a health supplement as well. Even viewing photographs of nature in a lab setting provided some psychological benefits, like improving executive attention for both older and younger adults compared with pictures of urban environments.

And perhaps unexpectedly, technology can also help you get your nature fix. While virtual experiences of nature are no substitute for the real thing, they are a viable option for people lacking access or mobility. In one 2019 study, watching videos of natural landscapes was found to relieve physiological signs of stress. A systematic review published earlier this year found that even an average of two minutes of exposure to these "simulations" of nature could reap nature's therapeutic benefits. For the more technologically savvy, virtual reality experiences of nature even show therapeutic promise. These virtual options make nature and its benefits more accessible when you can't enjoy them outside.

### HOW TO USE NATURE TO IMPROVE MENTAL HEALTH

Indoors or out, nature is good for your mind, provided you make time for it. Here are some suggestions you can incorporate to help you get your healthy dose of green:

- If you can get outdoors and stay safe by practicing social distancing, visit your local park or hike through a forest.
- · Go birdwatching either outside or at home.
- Start to expand your garden. Growing your own herbs and vegetables can be relaxing and also good for your diet.
- Try to get more natural sunlight in your home and workplace.
- Decorate your house with potted plants and art featuring natural landscapes.
- Check out nature documentaries on your preferred streaming service or online.
- Relax to the sounds of wildlife.
- Watch live streams of zoos and wildlife during breaks.

# TELETHERAPY - IS IT RIGHT FOR YOU?

### by The Pediatric Development Center

eletherapy. It has been one of the few golden nuggets that emerged from the embers of COVID-19. The pandemic set the entire therapy community on a new path to thinking about offering speech-language, occupational, physical, and feeding therapies in a whole different way. If you had asked me in January 2020 if I, the co-owner of The Pediatric Development Center (PDC), a private pediatric therapy practice with 2 physical locations, thought that teletherapy was a good service delivery model, I would have simply told you, "No." In fact, as the world was shuttering its windows against COVID-19 and we were looking at the reality that teletherapy was our only option if we wanted to continue to provide services, we started with a list of children who we did not believe could be served well via teletherapy. Now 10 months into our teletherapy journey, I am happy to tell you just how wrong I was on both accounts.

As therapy professionals, the practitioners at The Pediatric Development Center understand the importance of parent involvement in the therapy process and we espouse a parents-as-partners philosophy in our clinics. Moving online brought this concept to the forefront. For, not all, but many children, achievement in online therapy in a variety of ways hinges upon parent participation in the session. The therapist takes the role of the coach and directs the session through the physical presence of the parent. The child learns skills in their natural environment using their own toys, books, and household items. The parent learns skills that enhance their child's language, sensory, feeding, movement, and play skills. During sessions, the parent learns skills that ultimately grow the bond and connection with their child as "I did it" moments abound outside of the treatment session.

Although we love providing services in our beautiful and well-equipped brick and mortar offices, our geographic location dictates who we are able to serve. We have often thought about the children who would benefit from private therapy services, but live in areas that do not have clinics like ours within driving distance. Unfortunately, providing services in those regions seemed more a dream than a possibility. Teletherapy has completely opened up a bridge to reach children in underserved communities. Therapists are licensed by state, so that means we can provide services to children anywhere in the state of Maryland.

Historically, immuno-compromise has been another barrier for children to receive clinic-based therapy services. Therapy clinics have many people in and out of the office all day, everyday which may put children with illness at risk. This has always been a difficult decision for parents to make - does the risk outweigh the possible gain for a child with significant medical needs to

receive needed therapy services? Teletherapy strips the risk and provides a pathway to provide services for these children.

In addition to the increase in access to private practice therapy services, it has been our experience that teletherapy has improved families' ability to commit to consistent treatment sessions as evidenced by the reduction in our cancelation rate and has increased the ability of the child to generalize skills learned in therapy to the home environment.

If you are the parent of a child who is receiving therapy services via teletherapy, you can ensure success by:

• Committing to the therapeutic process: Success = Frequency + Consistency over Time (equation)

### FREQUENCY + CONSISTENCY = SUCCESS

TIME

- Coordinate communication between medical and therapy team
- Participate in all treatment sessions
- Practice strategies and skills learned in treatment between sessions
- Remember that development never travels in a straight line







The Pediatric Development Center, LLC has 2 locations in Montgomery County, Maryland and is serving children across the state via teletherapy through our new online clinic, PDCVirtual. Follow us on Instagram, Facebook, or visit our website at www.PDCandMe.com.



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



Email all submissions to: janet@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.

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