

ViewFinder

A FOCUS newsletter that frames and focuses life with children who are extraordinary and medically complex



“... Swimming is great for OI kids because it provides resistance training to increase strength and increase cardiovascular fitness, all in a medium that is low stress to bones and joints, which decreases risks for injury ...”

FAST Fins: Surprising Outcomes

By Allison Palestrini

Like many parents of special needs kiddos, I can feel like I’m living Dory’s mantra from *Finding Nemo* – “Just keep swimming ... Just keep swimming ...” – on a frequent basis.

Being blessed to parent our children, Reid (age 9) and Genevieve (age 6), who both are affected by Osteogenesis Imperfecta (OI) type 1 (brittle bones) is not without its unique challenges. Keeping the kids safe from fractures and active is a tall order, but swimming is a wonderful fit; which is why I was thrilled when they both dove head first into FAST Fins with FOCUS this season.

Reid returned for his second season with the team and Genevieve began her first. Team sports are tricky for us to navigate. Being a part of the FOCUS swim team builds confidence, sportsmanship, and some previously unforeseen physical health benefits.

In 2020, we met with Genevieve’s orthopedist and received the diagnosis that her spine had a curvature. After researching possible treatment options during the pandemic, we decided on a “wait and see” approach of monitoring her back for any changes and further exploring options in the future. Since then, we have received the incredible news that her curvature has lessened – which honestly, I was unaware was even a potential outcome! I was hoping we would just stay the same when I walked in for the check up. While looking at her side-by-side x-rays, my mind reeling that improvement was happening, I asked our doctor how it was possible. OI and scoliosis is a multifactorial problem but increasing Genevieve’s activity and

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From the Editor... The Value of Community

by Frances McBrayer

In the last 16 months, I have learned that FOCUS creates community for children with disabilities and their families.

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I know how much it means to my family, but every single family that is involved with FOCUS has their own story. And even though all of our children are different, the common theme is the community that FOCUS creates – for parents, for kids with disabilities, and for siblings.

One example of this community is our Friday night share group. Each week, whether it is your first session or your fortieth, our FOCUS parents are there for each other –all over Zoom without having to leave home or find sitters for our kids. We share laughs, tears, advice, complaints, fears, and successes. Knowing that other people understand the realities of our everyday lives is invaluable.

Another beautiful example just happened recently. Audrey LeSage, FOCUS Program Coordinator, and I had the opportunity to attend the 18th birthday party of one of our FOCUS teens, and it felt like a mini FOCUS event. As friend after friend arrived, all of them were part of the FOCUS teen and young adult program. All of them were there to celebrate their friend and this birthday milestone. Whether or not these families found themselves through FOCUS initially, I would like to think that being a part of FOCUS has helped to enrich the relationships that the boys have with each other. That certainly seems to be the case with many families that I have met during my time at FOCUS.

We call members of our network our FOCUS family. If you have not experienced this feeling of community and belonging, please reach out. Our FOCUS family is always ready to embrace new members!

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Milestone Monday

By Judy Hammett (proud mom of two very special boys and four angels in heaven)

Mondays have always been a busy but fun day in our home. While Shawnee and Kimberly and Blake were all in school, they were always happy and ready to see their buses coming down the street. They loved riding the bus and going to school.

Kimberly is now in Heaven and Shawnee has graduated, so we only have one bus coming each day, or we did until the Pandemic hit a year ago. Blake has mild CP, BPD, breathes through a trach and is fed completely through a G Tube in his stomach. He has a history of seizures and sleep apnea.

When we brought Blake home from the hospital, we were told he would probably never be able to do much on his own and probably not live more than 2 to 3 years. But they told us that they hoped they were wrong, and we knew they were! He has always been the happiest little boy in the entire world. Today he is walking, playing with toys, and making sounds, but no words yet.

He recently reached a new milestone ... our Monday accomplishment. He loves to sit on the floor and pull his toys out and spread them all around him. Then he leaves them for mom or his nurse to pick up. That was not going to work, we told him. So we said to him, "Blake pick it up and give it to me." (We

would point at one of the toys). After being told to give it to me a couple of times, he did it! We nearly passed out. We clapped and said what a good job that was. We then tried going for another toy. Same request ... toy handed over. He did this until all the toys had been picked up and handed to us. Now all we have to do is ask him to hand us whatever it is we need him to pick up and he will do it. Needless to say we are so very proud of him.

By the way, he is now 8 years old.

FOCUS celebrates Milestone Mondays on Facebook and Instagram, and we would love to help you highlight your child's accomplishments. The milestone can be large or small ... because all of it deserves celebration! Email LaShayla@focus-ga.org and tell us about the amazing accomplishments your child has made.

FAST Fins: Surprising Outcomes

strength did help her back as she also grew. Genevieve's #1 physical activity is swimming.

Swimming is great for OI kids because it provides resistance training to increase strength and increase cardiovascular fitness, all in a medium that is low stress to bones and joints, which decreases risks for injury. Increasing muscle strength directly increases bone strength. The benefits of cardiovascular and pulmonary health in OI kids cannot be underrated. The lungs are affected in many people with OI and working our lungs to max capacity is very important.

Swimming is great for self-esteem and confidence – it offers an activity that OI kids can do and do well.

Swimming is also good for OI parents – it gives us a small sense of security – knowing we are providing an activity that (hopefully) our kids enjoy while at the same time making their bones, muscles, and lungs strong.

While I understand the solutions for our kids will be as unique and individual as they are, I wanted to share that the FAST Fins program has countless benefits.

Here's to flipping the "just keep swimming" mantra in our minds from survival mode to that of thriving in the pool with the extra safe physical activity made possible by the team at FOCUS. We hope to "just keep swimming" for all around well-being for years to come!



Coming Up: Camp Hollywood 2021!

Camp Hollywood is back in-person this summer, and we can't wait to see you! Our activities each day will be inspired by the following movies: *Frozen 2*, *Toy Story 4*, *The Lion King*, *Pokemon Detective Pikachu*, and *Spider-Man: Into the Spider-Verse*.

Here is our summer schedule:

June 7-11 th :	McKendree United Methodist Church – Lawrenceville
June 14-18 th :	Oak Grove United Methodist Church – Decatur
June 21-25 th :	East Cobb United Methodist Church – Marietta
June 28-July 2 nd :	East Cobb United Methodist Church – Marietta
July 5-9 th :	Virtual Camp Hollywood Week*
July 12-16 th :	First Baptist Church – Peachtree City

*If you missed registration for our in-person camps, or if you're just not ready to come back yet, we are still taking registrations for our virtual Camp Hollywood program! The camp registration fee is \$25 and includes pre-recorded videos of activities that you can do at home as well as live Zoom events the week of July 5th. Your camper can participate in virtual group sessions with our FOCUS staff and other campers, live music therapy via Zoom, and an outdoor event for families – all of which will take place July 5-9th. Register here: <https://focus-ga.org/family-portal/>. We would love to have your child participate!

FOCUS Flashback: Turn the Nightmare of Family Game Night Into a Sweet Dream

By Celia Lawton



(Revisiting an article from the FOCUS newsletter in Spring 2012)

Family Game Night has always been an extremely painful experience for my family – my husband, twin boys with autism, and me. When my kids were very young, they had absolutely no interest in playing games. They preferred, instead, to perseverate on letters and numbers, draw pictures on our walls, and generally run amuck throughout our house.

As their cognitive and reasoning abilities strengthened with age, they still did not like games for a variety of different reasons including: the inability to stay on task for the entire length of the game, as well as the inevitable meltdown that would occur when either one of them would lose.

In the midst of these meltdowns, my husband and I would race to the TV in search of a video that might distract the losing child, overcome the meltdown, and generally reduce the amount of interaction that any of us might have to have with each other.

But one day, a special needs teacher at school introduced my kids to a game called

Sleeping Queens. (I am not affiliated with this game in any way, nor do I get any benefit from sharing it with you, other than the hope that your kids might enjoy playing it as much as mine have over the years.)

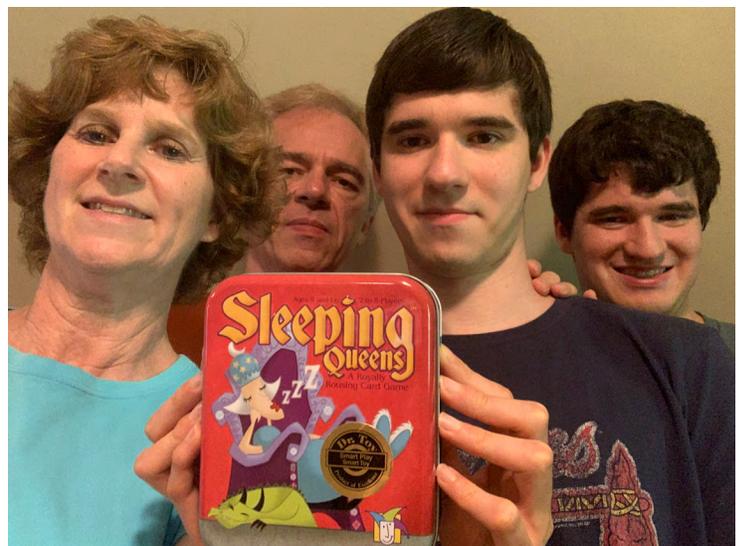
The rules of the game are easy to follow. That's because a six-year old girl thought of the concept one night when she could not fall asleep. There are several queens in the deck that are asleep and must be awakened. The most common way to wake them is to discard matching pairs of number cards, or to discard number cards that form simple math equations ($1+2=3$). Once a queen has been awakened, the player gets to keep that queen. But beware, there are a variety

of special cards mixed in the deck such as Kings, Dragons, Knights, and Potions that wake, protect, steal, and "re-sleep" the queens, respectively! The first player to collect a predetermined number of queens (or a predetermined number

of points associated with the queens) is the winner.

The cards in this game are very engaging, which is the main reason why my kids enjoy playing it. After all, who wouldn't like a Tie-Dye King, a

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FROM PAGE 5
Family Game Night

Cookie King, or a Pancake Queen? And here's another reason why this game is so popular in my household: it only takes about 15 minutes to play it from start to finish. So children, in general, are able to stay interested throughout. Finally, as a parent, I found that I could improve the odds of a child's winning through the cards that I selected to play, which often thwarted many a meltdown that might have occurred. Nevertheless, don't be mistaken that Sleeping Queens appeals only to the very young. There are numerous scenarios that occur throughout the game to make it interesting and challenging for players of any age.

So if the thought of family game night leaves you tossing and turning in bed at night, give Sleeping Queens a try. And maybe, just maybe, your family will fall under its sweet spell! (For more information, visit <https://gamewright.com/product/Sleeping-Queens>.)

Update Summer 2021: *My sons were seven years old when they began playing Sleeping Queens, the card game that is featured in this flashback article. Eight years later, when they were fifteen, I wrote this review for the FOCUS Newsletter because our family was still playing and enjoying the game. Fast forward to 2021. My sons just turned twenty-four, and Sleeping Queens remains a favorite for everyone in our household. It's fascinating to me that a simple game for grade school students can at the same time offer stimulating play for adults. That's why I decided to "brush off the dust" on this archived article —because I wanted to introduce (and perhaps re-introduce) FOCUS families to this "sleeper" of a game.*

A Look Back: FAST Fins Spring 2021

"I liked the swimming award because it was wonderful and it makes me feel so good. My favorite part about swimming was being with my awesome coaches. It felt like I have gotten better and faster."

– Tyler Harris, FAST Fins swimmer

"Eli loved being on the swim team this spring! His favorite things were getting to spend time with his buddy Joey in the pool and winning those ribbons at the swim meet! Thank you so much to Audrey and all the staff for making it possible!"

– Julia Urshansky, FAST Fins parent

"Thank you for finding a way for our loved ones to be actively engaged."

– FAST Fins parent

FOCUS FAST Fins fall season will start up in late August. Registration will begin in mid-July. Look out for the registration announcement in the FOCUS weekly email sent on Monday afternoons!





Our favorite part of FAST Fins (from FOCUS parents):

**“Coaches, encouragement and a self-paced environment” ... “Getting to see friends and the swim meet”
... “Structure, activities, being in the water” ... “He loves all of it! Thank you so much!” ... “Loves to swim.
Likes physical activity/ getting out of the house!”**

In My Own Words: Thank you for helping me get a van lift

By Salomon Santos

Since getting the wheelchair-accessible van, it has been a blessing. My family and I don't have to wait hours for our transportation or get up extremely early to be ready. Everything seems within reach now.

We don't have to struggle to find someone to give us a ride to an appointment or the hospital. I am grateful to FOCUS for raising money and helping me and my family with a vehicle that will be essential for me and my future. I am committed to getting my permit in the near future along with my license. Thank you FOCUS and to all the donors for making one of my dreams come true.

And a word of thanks from Salomon's Mom:

Mi nombre es Angeles Santos, y Salomon es mi hijo. Este sueño de poder tener una ven para nosotros y la transportación de Salomon es una bendición. Esto es una gran ayuda para Salomon cuando ya empiece a manejar. Gracias a todos por ayudarnos.

My name is Angeles Santos and Salomon is my son. This dream of ours to be able to acquire a wheelchair accessible van for transportation is a blessing. This is a great help for all of us, especially Salomon when he begins to drive. Thank you to everyone that made this possible.

The FOCUS equipment program provides granted and loaned equipment that is not covered by Medicaid or private insurance for children under 21, including up to \$5,000 towards a wheelchair van lift for those families who qualify. If your child is in need of equipment to help make everyday life better, please reach out to Devi@focus-ga.org for more information.

You can also check out the items in our loaned equipment library anytime at <https://focus-ga.org/loaned-equipment-library/>



FOCUS Fundraising

Thank you for helping to make our spring efforts successful!

For the Love of Children Gala

FOCUS held its *For the Love of Children* gala on March 18th, 2021, and we went virtual this year! We were able to feature six videos with children and families highlighting more of our FOCUS programs and reaching a broader audience than we have been able to do at past galas. One donor told us that she has supported FOCUS for years, but thanks to this virtual format, she learned about FOCUS programs that she did not even know we had! Even though we were sad not to be able to be together

in person, we are extremely grateful for the support shown.

THANK YOU to all of those who took the time to make videos, to watch the broadcast, to invite friends, and to donate. We could not have done this without our generous sponsors, many of whom are members of our Board of Directors, Advisory Board, and Honorary Board.

Please see the list of sponsors and donors on page 10.



FOCUS held its 21st Annual Golf Classic on April 20, 2021 at The Manor Golf & Country Club in Milton, GA. More than eighty golfers came out to support FOCUS, and once again, Curt & Trevor Smith, Dan Dubowski, and Przemek Szczepanik chaired the event. We are incredibly thankful for their commitment to FOCUS.



Curt Smith shared his experience as a FOCUS parent and provided a great example of the impact that FOCUS has had on his family's life. It was a great event, and we appreciate the generosity of our chairpersons and our sponsors! See the list of golf sponsors on page 11.

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For the Love of Children Gala

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For share groups, workshops, and if your child is in the hospital, contact jaide@focus-ga.org

For adapted swim team, teen & young adult activities, and overnight camps, contact audrey@focus-ga.org

For information about day camp programs, family activities, and family retreats, contact cesar@focus-ga.org

For information about Equipment Grants, contact devi@focus-ga.org

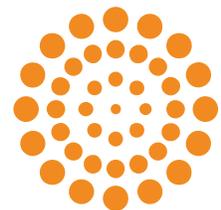
To volunteer for any and all programs and for questions about how programs are continuing during the pandemic, contact brian@focus-ga.org.

Check our calendar at www.focus-ga.org for the most up-to-date information!



Huge thanks for those who created Facebook Giving Campaigns for FOCUS!

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February 26, 2022



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