May/June 2014

Volume 31 Number 3



A PATH for Dalia

by Rebecca Cheskes

Fun omfort.

In just a few days, our family will begin a new journey - or PATH - with our 12-year-old daughter Dalia. PATH stands for Planning Alternative Tomorrows With Hope, a visioning process that takes place at a group meeting with a facilitator. A PATH can actually be done for anyone, but is often used for people who have special needs. FOCUS led me down this path when I attended the FOCUS Parent Education Conference in January and went to the workshop about creating a Microboard, a person-centered, non-profit entity formed by a small group of committed friends and family members who volunteer to help plan, develop and maintain the ongoing services necessary to support one person with a disability.

During the Microboard workshop, Todd Copper shared his story of how his family helped him form a Microboard; first he set goals for his life with a PATH. I had NO idea what these terms were ... PATH microboard person-centered planning ... but what I heard really resonated. The main idea is to determine what makes life meaningful; for most, that is family, friends, work, fun activities, etc. Well, aren't these also the things our loved ones with special needs should have? I wondered if I could really make this kind of life a reality for my daughter, who is non-verbal, developmentally delayed, and has a VERY hard time with new experiences.

I wasn't sure.

Dalia has partial agenesis of the corpus collosum. This basically means that the two hemispheres of her brain are not completely connected by the "superhighway" of the corpus collosum. She is on the autism

spectrum and uses a communication device and sign language to make her needs known. Although I have always worked hard to advocate for her, there were many moments that I questioned how much she would actually be able to do in her



life – I did not always believe in her abilities. But, I have learned recently, that she is also EXTREMELY capable!

I started trying to understand Dalia more by watching her reactions to various activities with greater intensity. I shared her accomplishments via email with ALL of her therapists, public school AND private, which I have never done. She has done things recently that I never thought would be possible!

I discovered that:

- Dalia enjoys painting pottery I had never taken her because I didn't think she would like it! She went with the Friendship Circle, a local organization and had a great time.
- Dalia likes looking at *Teen Vogue* with her private OT and writing words like "purse" and all the various colors of purses in the advertising shots.
- Dalia plays games with her "special friends" at school, likes to watch and play tetherball with them, and enjoys their company.

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MISSION STATEMENT

FOCUS understands and supports the unique needs of families with children who are medically fragile or have significant developmental or physical disabilities. FOCUS offers comfort, hope and information to parents; accessible recreational and social programs for children and teens; and fun, inclusive activities for the entire family. A nonprofit founded by parents in 1983, FOCUS continues to embrace and strengthen metro Atlanta families.

SUBSCRIPTION INFORMATION

For subscription information, please call FOCUS at (770) 234-9111 or visit our website at www.focus-ga.org. Annual subscriptions to the newsletter are \$15 for families (waived if necessary) and \$30 for professionals.

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From the Editor by Lucy Cusick

Did you miss anything in the last FOCUS newsletter?

The newsletter is always a work in progress, until the very last minute, when we have to go to press! We know that print is passé – why do we still go to the expense of printing and mailing a newsletter when email is practically free? Well, for several reasons ... parents tell us they like to toss the newsletter in their purse or car to read when waiting at therapy or doctor appointments. They might then give the newsletter to another parent in the waiting room – or pass the newsletter on to a relative who might benefit from one of the stories. Some parents say they have keep all of their newsletters so they can read them again – how cool is that? True or not, sure made me feel good!

Reading newsletters, making lists, and juggling schedules seems to be the norm. The theme of life these days seems to be how to do more and more, without an increase in hours per day. Our kiddos run from school to therapy to doctor appointments – all of which are necessary. Add in work, grocery shopping, errand-running, and meetings at school, church, plus an occasional hobby and you're already out of time. Wait! We forgot siblings, sports, grandparents, repeated hospitalizations, Facebook updates, wheelchair clinics, and holidays. Nothing can be cut without someone feeling left out.

Being a parent is certainly a job – unpaid, except, of course, for the smiles, steps, words, and belly laughs. But, they don't pay the bills – and the everyday-ness of being a parent is tough. Unload the dishwasher just to re-load it. All the laundry is clean and put away ... until bedtime when everyone undresses and the hamper is full again. Three meals a day. Really? Can't we just do two today?

Being a parent of a child with special needs adds even more to the job description! Medications, equipment delivery, oops a seizure, and real life just beats you down. It's hard to take time to look at the big picture – we're too busy flipping through the snapshots!

We at FOCUS sure don't have all the answers ... heck, sometimes we don't have ANY answers! But, ignoring a problem rarely makes it go away. Even if the problem can't be solved, maybe it can be broken down – and parts of it made better.

Which brings us to what was missing in the last FOCUS Newsletter! The calendar is always a moving target ... planning events two months ahead – with dates changing hourly. And once it's printed, it's hard to change! We decided to experiment with NOT including the calendar in the newsletter – if we had complaints, we could always reverse the decision. We had one comment – not really a complaint!

So – refer to the FOCUS calendar on-line and make a note of upcoming events. We have activities almost every weekend – lots of Comfort, Hope, and Fun to be had at FOCUS! ■

www.focus-ga.org/calendar/

A Match Made In Heaven

By Christy Aldredge

ordan came to us as a surprise gift some 27 years ago. Medical knowledge at that time predicted that because of her diagnosis of lissencephaly, she very likely would not survive to celebrate her fifth birthday. Medical knowledge was wrong!

Our journey with Jordan has been a long, and sometimes tenuous, one. Something of everything has happened along the way. But, with heartache has come joy, no more so than Jordan's fateful pairing at FOCUS Camp Hollywood with volunteer Hal Davies.



"Mr. Hal," as he was known to his many friends, passed away

suddenly last year. He was a member of those now known as "The Greatest Generation": a devoted husband to his beloved Shirley, a proud father and a doting granddad. He tirelessly volunteered his time to help those less fortunate and was an ambassador in the grandest way for those with special needs. Life threw him some curves. He never complained. He was a prince of a man whose faith was strong, and he maintained an abiding love for his country throughout his life. He was truly a man who led by example, but most of all he was our friend.

I don't recall how many Camp Hollywood's ago we first met Mr. Hal. (*Editor's Note: Jordan and Mr. Hal met at Camp Hollywood in 2004.*) The first day of camp is often a little crazy until all the campers arrive and get settled in their groups. On the first day that year, the camp director asked Mr. Hal if he could help Jordan for the morning; he later admitted that he was hesitant to work with the campers because his medically fragile grandson died and he was afraid he would be too sad. But, when asked, he put his fears aside – and he and Jordan bonded instantly! He fed her lunch, sang with her in many camp musical productions, pushed her wheelchair from activity to activity, and comforted her if she was having a very rare bad day. Every afternoon he would greet me with a synopsis of their day and always would ask, "Is there something I can do to help you," as if all of the above wasn't enough!

To say that he blessed us with his friendship would be an understatement. We received so much more from having known him! Our Camp Hollywood's with Mr. Hal were a yearly event until 2008, when Jordan aged out of the program. However, the friendship did not end because, over the years, the bond with Mr. Hal extended to include our entire family. He became a fixture at Jordan's baseball games with the North Metro Miracle League, and we eagerly looked forward to his monthly visits with us in our home. Every Christmas he brought Jordan a star ornament for our Christmas tree. It was a symbol of their meeting at Camp Hollywood, Where Everyone's A Star. She was his star!

In February 2013, we planned to share a table with him and his family at the annual FOCUS "For the Love of Children" gala. We could not attend because of a last minute conflict, and I promised him that nothing

FOCUS Fund Raisers!

Support FOCUS fund raisers AND the programs FOCUS offers by attending FOCUS fund raisers ... and bring friends! Proceeds go to FOCUS programs which are offered at a reduced (or no!) cost to children and families!

May 7, 2014

14th Annual
FORE FOCUS GOLF CLASSIC
at Bear's Best Atlanta.
Golf for fun and "fore" FOCUS!!

August 16, 2014

5th Annual
SUMMERFEST AT
SWEETWATER BREWERY
Cheers to summer and FOCUS camps!
Enjoy brewery tours & tastings,
Willy's Mexicana Grill,
cornhole tournament and music!

October 18 & 19, 2014

Ride for TEAM FOCUS in SPIN FOR KIDS Raise money for programs FOCUS offers at Camp Twin Lakes!

Email lucy@focus-ga.org for information on any of these events. FOCUS fund raisers support FOCUS programs and help keep the cost low to families!

would stop us from joining him the next year. He called a few days later and left a message, thanking me for honoring him with a donation to FOCUS. I never had the chance to call him back because he died very suddenly.

We miss Mr. Hal and were not ready to let him go. I thank Jordan every day for bringing him into our lives; God truly blessed us by bringing he and Jordan together at FOCUS. We are forever grateful.

Rest in peace, dear friend.

Until we meet again, Christy, Mike, Jordan, Courtney and Lane Aldredge ■

Ongoing FOCUS Programs

"Looking Back" spotlights events that occur annually – we should also remind families of the ongoing programs at FOCUS!

Extra Special Saturday respite is offered in six locations each month (during the school year). Children enjoy unstructured play time with trained caregivers and volunteers so parents can enjoy a morning off to run errands, have lunch, or take a nap! For information, contact Karen@focus-ga.org

FAST Fins (FOCUS Adapted Swim Team) has grown to eight teams!! Swimmers perfect strokes, work on endurance, and learn teamwork; teams compete in a meet at the end of each season. For information on FAST Fins, contact Mackenzie@ focus-ga.org

FOCUS volunteers visit children when hospitalized at Children's Healthcare of Atlanta at Scottish Rite or Egleston. Moms love receiving a *Pampering With A Purpose* rollup bag filled with Mary Kay products or (if a member of the 'frequent hospital club') a giant chocolate bar and other eat treats; children love fleece blankets, books, or stickers. We do occasionally miss visiting, but do our best! For information, contact elizabeth@ focus-ga.org

Teen/Young Adult Groups are monthly social gatherings for teens/young adults who love activities but need some structure and extra help. For more information, contact Mackenzie@ focus-ga.org

Share Groups are offered in eight locations around metro Atlanta each month! Facilitated by parent volunteers, share groups are an informal time to discuss the frustrations AND joys of parenting a child with special needs. Some groups are choosing to continue through the summer! Mark your calendars and watch the weekly emails for more information about these summer groups (which correspond to where Camp Hollywood is that week!):

Thurs., June 5, 10:15 – 11:30 am Alpharetta at Starbucks 11770 Haynes Bridge Rd.

Thurs., June 5, 10:15 – 11:30 am Suwanee at Chick-fil-A 2835 Lawrenceville Suwanee Rd

Thurs., June 12, 10:15 – 11:30 am Johns Creek at IHOP 11720 Medlock Bridge Rd.

Tues., June 17, 10:15 – 11:30 am Marietta at Chick-fil-A 1201 Johnson Ferry Rd

Thurs., June 19, 10:15 – 11:30 am Kennesaw at Starbucks 745 Chastain Rd NW Tues., June 24, 10:15 – 11:30 am Marietta at Chick-fil-A 1201 Johnson Ferry Rd

Wed., June 25, 10:15 – 11:30 am Buckhead at Starbucks 2900 Peachtree Rd NW #310

Wed., July 9, 10:15 – 11:30 am Chick-fil-A at Northlake Festival 3967 Lavista Rd

Fri., July 11, 10:15 – 11:30 am Chick-fil-A in Newnan/Peachtree City 707 Highway 54

Also Coming Up at FOCUS!

(Always check <u>www.focus-ga.org</u> for details!)

May 4

FOCUS Day at Six Flags Over Georgia More than 800 tickets were pre-sold on-line! Sorry, no more tickets are available.

May 10

FAST Fins Intramural Meet Mountain View Aquatics Center Come cheer on our swimmers and check out our FAST Fins program!

June 14

 3rd Annual Daddy-Daughter Dance & Dessert Saturday, June 14, 3:00 – 5:00 pm
 Mt. Bethel United Methodist Church Watch your email for more information!

Fridays at FOCUS!

Workshops at FOCUS ... on Fridays ... must RSVP to elizabeth@focus-ga.org. Fridays at FOCUS will take a break for June & July & resume in late August.

May 2

NOW/Comp waivers by Heidi Moore

May 9

Katie Beckett/Deeming Waiver by Debbie Dobbs

FOCUS Day Camps

For information on day camps, please contact FOCUS at inquiry@focus-ga.org Registration closes for day camps on May 9. Hurry!

- May 27 to May 30. Camp TEAM is a traditional outdoor day camp experience, offered at Mercer University in Chamblee for campers ages 7 to 13. Camp TEAM has only a few spaces in certain age groups ... apply quickly!
- June 2 to July 11. Camp Hollywood is a mostly indoor day camp where campers enjoy arts, crafts, cooking, science, music, and recreation based on the themes of popular children's movies. Some locations of Camp Hollywood have openings apply quickly!

Under the Stars Family Camps

August 8 – 10 at Camp Twin Lakes, Rutledge October 3 – 5 at Camp Twin Lakes, Will-A-Way

The theme for this year is "Under the Stars Wars!" Applications went out by email on April 16. We are anticipating family camps filling up quickly, but encourage families to apply online since cancellations always occur!!



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A PATH for Dalia

(Continued from page 1)

When I realized that Dalia enjoyed being with typical kids her age (or older), I decided it was time for me to find more social opportunities for her. Suddenly, I realized that my son Ilan, who is 9, is invited to countless birthday parties and playdates, but Dalia has NEVER had this type of experience.

My heart was heavy ... how would I make this happen for Dalia? Would anyone want to take my Dalia out for a fun activity, when all she seems to want to do is watch Barney videos at home? She attends a public

school that is NOT in our neighborhood, so I knew that I needed to turn to my community to brainstorm ideas for Dalia to start interacting with more kids her age. PATH gave me the format to do just that - people gather to discuss a plan for a happy and productive life for Dalia!

I am fortunate that I have tutored 12and 13-year-old students for their Bar and Bat Mitzvah ceremonies for the last 16 years, so I have invited many of these students and their families to the meeting. In addition, some of her current and former teachers and therapists are coming, along with a new friend that I met at the most recent autism conference!

Person-Centered Planning

by Stacy Ramirez

Person-centered planning is a process that empowers people with and without disabilities to define the direction for their lives. It focuses on supporting an individual's goals and dreams by utilizing their gifts and talents. This emphasis ultimately leads to greater inclusion as a valued member of community.

A PATH is one of the processes used to guide person-centered planning. This process enables people to choose their own pathway to success. An individual invites a core team of supporters they trust to help achieve his/her goals. The team, or circle of support, simply helps the focus person figure out how to best fulfill his or her ultimate goal, the North Star.

If the circle of support creates a non-profit entity, it becomes a microboard. The PATH process is utilized by the microboard to develop a mission and focus that addresses the individual's support needs on their journey to a fulfilling self-determination, goal-driven life.

For information on PATH, please contact Sramirez@gsu.edu. For information on microboards, go to www.gamicroboards.org.

I am so grateful to have FOCUS and its great programs for our family; once again, FOCUS brought me the information about hosting a PATH for my sweet Dalia. I have read every newsletter since 2002, shortly after my daughter was born. Lucy was one of the first people that I talked to during the weeks while I waited for Dalia to come home from the hospital. This path is easier because of my FOCUS friends!

The Voice of Democracy

The following speech was written by Tim Neja, 19, winner of the VFW's Voice of Democracy competition in October of 2013. His parents, Tim and Jody, write, "This would never have happened except for the love we received when he was little from people like our FOCUS friends."

Why am I optimistic for America's future? I have two reasons why my view for America's future is optimistic. America is a land of great opportunity where dreams come true, and even a place



where anyone can achieve success. America is a place where people are willing to help others to earn that chance. I'm thankful for being in a great nation full of caring and hope, with people willing to help others find what is in their hearts.

Here is my story and it reflects my optimism in a truly fascinating nation like America, which has helped me achieve many accomplishments. I have autism. It is a communication disorder but I can still enter a speech contest, because this is America. My parents never understood the way I acted when I was little because they didn't know I had autism. My speech was delayed and I didn't learn how to talk until I was six or seven years old. I have a very strong memory and it has been this way for many years. My memory was so strong that I could remember some of the things that happened was I was little, sometimes even when I was starting to speak. I could remember when a movie came out in the theatre or even on video, and I remember so much about the entertainment media. I have some goals that I have done and others that I want to do for my career. The goals I have accomplished include that I am graduating from high school this year. I've played tuba in symphonic and marching band for all four years, and I've been in leadership in the band for two years. I have been in the Pope fencing club for four years as well, because I had interest in trying a new sport and wanted to challenge myself. I used to play baseball outside of school grounds for around 10 years. Now, when my schedule gets free, and if my dad needs help, I do coach the Challenger baseball team. Also, I started writing a screenplay because I had inspirations from other movies. I made my screenplay as original as possible and it is over 200 pages long. My future plans are to hopefully be involved in the movie

(Continued on back page)

Looking Back...

Alliance Theater for the Young. In March, FOCUS children AND families enjoyed a presentation by the Alliance Theater for the Young. Inspired by the fun and inventive children's songs of Woody Guthrie, Songs to Grow On invited children on a one of a kind journey across the country in search of the sounds of America. A tale of friendship, travel, and most of all the love of song, this unforgettable experience celebrated the joyful noise of harmony. Thanks to First Christian Church of Atlanta for hosting and to the Junior League of Atlanta for the delicious food!





FOCUS on Sibs. New in 2014! In the past few months, FOCUS offered three afternoons of sibling support at "FOCUS on Sibs." Dr. Jennifer Tumlin Garrett, trained and experienced in the Sibshop method, facilitated the groups with sibling mentors. Almost 20 siblings participated in a spirited mix of new games, reflecting the belief that brothers and sisters have a lot to offer each other, given the chance. Another session of "FOCUS on Sibs" will be offered in the fall; contact joy@focus-ga.org for more information.



This year at **the 31**st **Annual "For the Love of Children,"** FOCUS recognized Angie and Skip Weiland whose great love for their son Bret inspired years of dedicated service to families in similar situations. They work tirelessly and give generously to help other families in similar situations. Almost 400 guests enjoyed an elegant evening celebrating FOCUS! Special thanks to emcee Tom Sullivan and to the band The Helpers for their time and talent! See page 5 for a list of sponsors and donors.





The Voice of Democracy

(Continued from page 6)

business, like acting or screenwriting; going to college, being a movie critic or a game designer. These are the goals that I am reaching for. I think I could only do this in America.

The reason I am optimistic about our nation's future is because many people helped me very much. If I didn't have the amount of help that I did, I would've been far different than what I am right now. I had extra schooling, which started when I had preschool for two years and then kindergarten for two years. This is my America. I made friends with people from my family's church and also from school. This is my America. I have great friends in my life. This is my America. I have a family with five siblings that care very much. In my life of doing the sport and music activities I've done, my coaches did a great job and my fencing coaches are the best at what they do. The music directors of the band I'm in gave me the inspiration how to be a good leader and better player. I got to perform for the 70th anniversary of Pearl Harbor and met many veterans with the band in 2011. This is my America.

America didn't just help me, it helps everyone in this nation; my family, celebrities, the mentally or physically disabled, the poor, immigrants from other places around the world and minorities in our country.

Unlike the treatment our country gives to us, some other places aren't as helpful, some are corrupt, and some even evil. In a story I read Pyongyang: A Journey in North Korea, it's about a man who travels to the city Pyongyang and he notices that there're no mentally handicapped people in that country. Inside a train the protagonist rides on, a man sitting across from him answers that there is none and says that all North Koreans are born strong, healthy and intelligent but later tells him he only knows this because Kim Jong II said it. What the author means by this is that all of the mentally handicapped people were killed by the order of an evil government. It's one of the most despicable things that I've heard about in my life, and this reminds me of the Nazis holocaust. These are the two most despicable acts that I've learned about because the people are just full of as much hatred as possible and hope that others will die. In North Korea, they kill anyone who is a mentally handicapped person.

America is an outstanding nation that offers amazing opportunities for anyone that wants to lead to success. Our country gives anyone a chance for help if they need it so they can have success and their dreams could come true. We shall all be thankful for the greatest things our country has done for us, to help us to a successful life. This is my America and this is why I am optimistic.

"I may not be a film actor yet, but right now I'm a recording artist!"

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