



THE TMA FAMILY CAMP 2013

The Transverse Myelitis Association is a non-profit disease advocacy organization focused on supporting and advocating for individuals, caregivers and families of individuals living with rare neuro-immune disorders, which include Transverse Myelitis (TM), Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis Optica (NMO) and Optic Neuritis (ON). We support research and education to increase awareness, improve diagnosis and accelerate our understanding of these rare neuro-immune disorders to enable the development of novel therapies to help individuals living with these illnesses.

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When a child is diagnosed with a rare neuro-immune disorder, the entire family is impacted. It is the goal of our annual TMA Quality of Life Camp to create an inclusive magical experience for families. Camp is a place where ordinarily difficult circumstances are totally forgotten and the children's lives are transformed into what we would hope for these children in their daily lives... but often times, the medical, social, psychological realities just don't allow it. For many families, it is the only possible vacation where the entire family can participate and enjoy their activities together. We are grateful to everyone who makes this opportunity possible, starting with the incredible people at The Center for Courageous Kids in Scottsville, KY. We are so appreciative of the support we receive from our members. You are all very special participants in creating this magic. The only thing the children and their families have on their minds when they leave camp is *when are we going to be able to return!*

Sandy Siegel
President



The TMA Camp Experience

The TMA Family Camp provides a chance for children with rare neuro-immune disorders and their family members to experience the joys of camp and connect with others who have the same symptoms and conditions.

Families participate in a completely accessible camp that would otherwise not be possible due to the affected children's level of medical needs and physical impediments. The relationships formed at camp between these families create a support network that continues outside of the camp experience. For many of these children, they don't know another child with their disorder until they meet other children at camp. Through our camps, the parents, siblings and children with the disorders develop lifelong friendships.



2013 Camp at CCK

In A Galaxy Far Far Away was the theme of the 2013 TMA Family Camp held from July 24-28, 2013 at Center for Courageous Kids, Scottsville, KY.

36 amazing families attended camp from across the United States and from Canada, Scotland and South Africa whose children had been diagnosed with ADEM, NMO and TM.

Physicians and medical professionals from University of Texas Southwestern, Johns Hopkins University, Kennedy Krieger Institute and University of Colorado, Denver joined the campers and their families.

We were also honored to have members of the U.S. Paralympics, a division of the U.S. Olympic Committee, join us.



Importance of Medical Staff

The TMA Camp is not only about fun and relaxation. A team of highly skilled medical specialists dedicated to the research and clinical care of these rare neuro-immune disorders participates in the daily activities.

Families have the opportunity to interact and learn from the specialists, while also providing clinicians and researchers an opportunity to interact with them outside a traditional clinical setting.

This education is critical to improving care through the development of tools for self-advocacy.



Education Program

Physician and medical experts on rare neuro-immune disorders come from across the country to spend time with the families during camp and hold an interactive education program.

The education program covers all the rare neuro-immune disorders. Discussions include acute and long-term therapies, symptom management issues, emotional, psychological and cognitive issues, and rehabilitation. A great deal of critical information and perspective is exchanged during these sessions.

The medical volunteers interact with families outside of the education program during the camp day... at meals, on the dance floor, in the swimming pool, in the horse barn, at the fishing and boating pond.



The Family Experience

“Family camp is such a bittersweet time for our family. Sweet is the time we get to spend with amazing families and children, physicians and caregivers, who truly understand what our lives are like. We love to watch the freedom and acceptance our son feels to be himself and not worry about being different because of his wheelchair or how he walks. Bitter is the fact that such a rare disease binds what seems to be so many together. It is difficult to leave and head back home away from our TM family and the fun that is CCK. As we drive away from camp, we are already looking forward to the next time we can be together with our extended family!”

- The Whitney Family

Activities



Fishing at the Pond

“Fishing was epic, I liked picking up wiggly worms and camp was awesome!”

- Jack Winton, 6 years old



Horseriding

“We have truly found our home away from home. A place where nothing else matters but our TM family and friends. The memories that we have made here will last a lifetime...”

-Chris, Jessica, Sullivan, Sadie, Stella, and Shepherd Absher



Swimming

The swimming pool is one of the most popular places at camp. The zero entry pool allows children to easily get into the water, and as it is an indoor pool, they are able to swim regardless of the weather. There is a freedom that these children feel in the water, regardless of their physical disability.



Painting

Our society doesn't do particularly well in relating to people with a disability; there is a general discomfort, there are stares, and people don't know what to say or how to say it. It is often worse for children than it is for adults. At camp, these children are not people with disabilities... they are unique and wonderful children. There is no discomfort for any of these children and there is no staring. Camp is a celebration of their individuality and their wonderful characters. Camp is a place where kids can just be kids.



Arts & Crafts

The Arts and Crafts room at camp is a busy place. Each child assembles and paints a racecar to participate in Saturday night's Bowling Green 500. The race is announced with lots of cheering; and the show ends with a wonderful fireworks display. There are also many other crafts that the children work on during the week and creativity blossoms.



Messy Games

The Messy Games are initiated in much the same manner as the Olympics ... the teams begin marching into the arena, led by the CCK Messy Games Torch-bearer. Families come charging into the arena covered in paint to represent their red, green, blue and yellow lodges. It is a hard fought contest, but as in all things at CCK, everyone is a winner. Going through the Messy Games with the kids with ADEM, NMO, ON and TM is undoubtedly one of the most wonderful experiences you can witness as a parent and member of the organization.



Looking out for Family

“As a parent of a young pre-teen daughter with TM and other limiting disabilities, we were unsure what the TMA Family Camp at CCK would have to offer our Sarah. Well, we were overwhelmingly thrilled with the camp, the counselors, the families and the experience! It was so wonderful to be surrounded by such unconditional love and understanding! The second year was more magical than the first. Sarah had an absolute blast and so did her big brother!”

- The Robbins Family



Making New Friends

“TMA camp at CCK is exactly the way life should be, no awareness of differences, but an acceptance and an instant "familial-like" connection. It has been a phenomenal experience for our whole family. We have made lifelong friendships and an amazing support system.”

-The Gum Family

But most of all....



Smiling

“Camp was truly amazing! The fishing was my absolute favorite activity!! I caught two catfish and a largemouth bass. I also loved hanging out in the gym during free time playing basketball with all of my new friends! All of the counselors were super nice and a ton of fun. The Messy Games were so crazy! I loved camp and cannot wait to go back next year!”

- Riley Blee, 12 years old



... And Smiling

“Gabby has been a different child since we attended camp. She seems to have gained more of an incentive to work hard at her therapies.”

- The Inscho Family



... And Smiling :)

“I felt like I was having the time of my life... to me you could not see that anyone had a disability because everyone was having so much fun! ”

-Bridget Gum, 12 years old



We can't wait until next year!

Coming together from across the country and around the world, as a rare disease community is a truly profound experience that is difficult to convey in words.

Camp is a place where these children can be children and parents and siblings can actively experience the resulting joy from this Quality of Life Camp.

Camp is a unique opportunity for both young adults and children to interact with each other, learn from each other and truly have an impact on their quality of life not only today but also and especially in the future.

For more information about camp visit www.myelitis.org/camp

A Special Thank You to our 2013 TMA Camp Sponsors



The Roles Family Foundation

...and to our community members who support our mission

