THE TMA FAMILY CAMP 2014

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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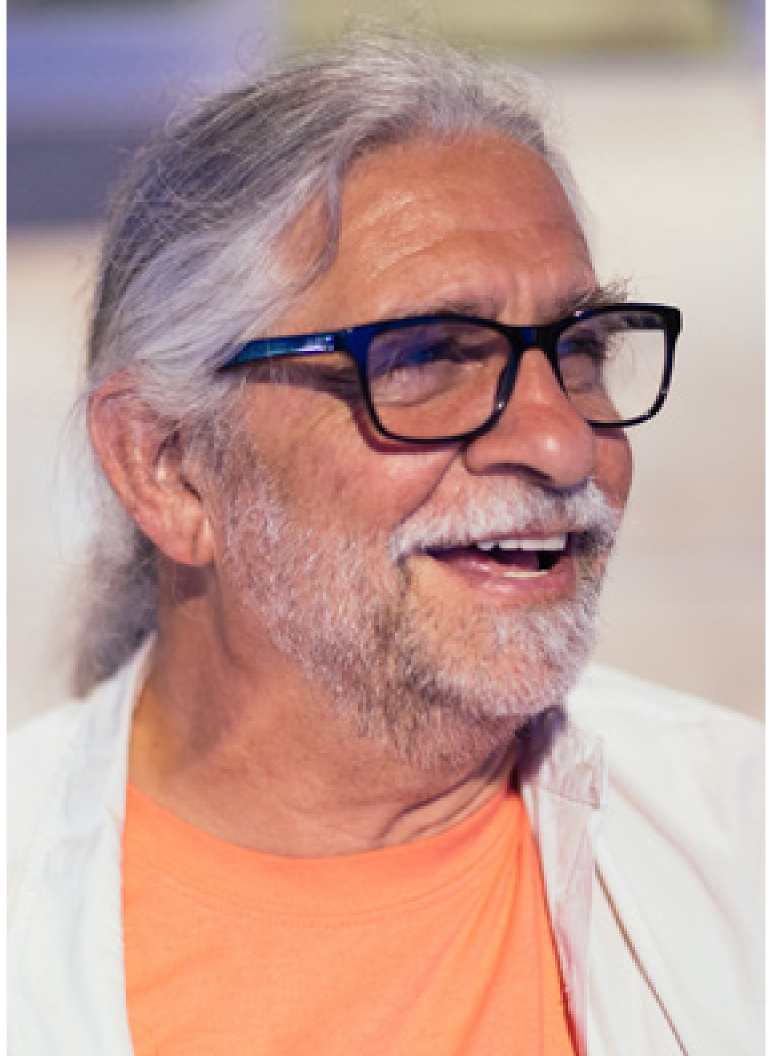


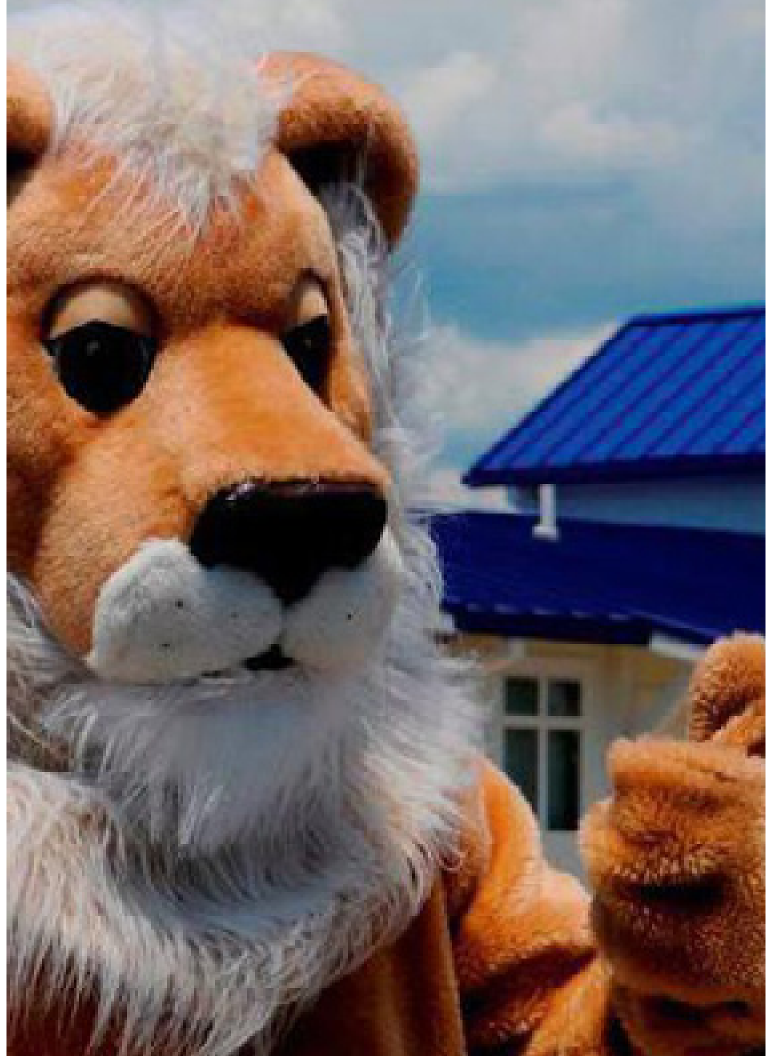
When a child is diagnosed with a rare neuro-immune disorder, the entire family is impacted. It is the goal of our annual TMA Quality of Life Camp to create an inclusive magical experience for families. Camp is a place where ordinarily difficult circumstances are totally forgotten and the children's lives 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 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 at camp. Through our camps, the parents, siblings and children with the disorders develop lifelong friendships.



2014 Camp at CCK

University Week was the theme of the 2014 TMA Family Camp held from July 23-27, 2014 at Center for Courageous Kids, Scottsville, KY.

36 amazing families attended camp from across the United States and from Australia, Canada, China and Norway.

Physicians and medical professionals from the University of Texas Southwestern, Cincinnati Children's Hospital Medical Center, International Neurorehabilitation Institution, Kennedy Krieger Institute and from the Board of Directors of The TMA joined the campers and their families.

Dr. Anjali Forber-Pratt, a paralympic medalist in the sport of wheelchair racing of the U.S. Paralympics Team, from The University of Kansas joined The TMA Family Camp.

Importance of Medical Staff

The TMA Camp is not just about fun and relaxation. Highly skilled medical specialists dedicated to the research and clinical care of these rare neuro-immune disorders attend camp with the children and families.

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

Physicians 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 Inscho Family

The Family Experience

“Having specialist doctors taking the time to listen to my daughter's problems, struggles and issues was healing in itself. Finding out things we did not know and having a plan for what has to happen next was amazingly comforting and reassuring. After years of struggles and frustration, in just a few hours we had more information, knowledge and a plan to make things better from the world's leading experts.

On top of this amazing experience, I also had endless hours of joy watching children and families laughing and having fun. You could just see how the stresses of daily life disappeared as they participated in the many fun activities hosted by CCK. It was truly heart warming. Not to mention the doctors and medical staff getting stuck into the fun too! How absolutely brilliant for children and their families to experience doctors this way and build bonds of trust and friendship! ”

— Susi Tuita

The Youth Experience

“Camp is truly life changing. The friendships that are made extend long after the camp ends. Knowing that there are others going through the same experiences reassures you that everything will work out in the end. ”

— Matthew Debly

Activities

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.

Music

Arts & Crafts

The Arts and Crafts room at camp is a busy place. Various projects are available for all skill levels from creating colorful paper lanterns to pounding together and putting personal touches on a race car, birdhouse, or a myriad of other choices in the Woodshop. Hammer, nails and even wood-burning aren't off limits at CCK (with the supervision of parents and staff, of course!). There are many crafts the children work on during the week and it is an awesome sight to see their creativity blossom.

Horseback Riding

> “We will always remember his smiling face when he rode the horses.”
>
> — Green Family

Archery

> “Archery is so cool! I fell down a lot when I was standing up to do it but I am really good when I am in my wheelchair and can do it. It was awesome!”
>
> — Schuyler Whitney

Bowling

> “He was also able to go bowling again (with his opposite hand) after two years.”

— Green Family

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.

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

Making new Friends

But most of all...

Smiling

… And Smiling

... And Smiling

... And Smiling :)

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 2014 TMA Camp Sponsors

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