



Off to Camp

Don't let your child's neurologic disorder keep him or her from enjoying sleepaway camp. Our guide will help you find the perfect match.

BY GINA SHAW

As summer approaches, millions of parents help their kids pack trunks for sleepaway camp. They write their children's initials on the tags of their clothes with permanent markers and pre-address and stamp envelopes in the hopes that their youngsters will actually remember to write a couple of notes home during their time away.

Sending your child off to camp for the first time is a huge emotional leap: Will he be homesick? Will she eat decent meals? Will the counselors keep my child safe?

These questions loom even larger when your child has a significant neurologic condition—so much so that many parents of kids with seizure disorders, muscular dystrophy, cognitive delays, or brain cancer may conclude that sleepaway camp just isn't an option.

But almost every child, no matter his or her disability or medical condition, can enjoy all the experiences of a typical summer camp: arts and crafts, swimming, fishing, hiking, archery, capture the flag, s'mores and ghost stories by the fire, and making lifelong friends. In fact, camp can be even more beneficial for kids with neurologic conditions and their families than for their neurotypical peers, says pediatric neurologist Bruce H. Cohen, MD, FAAN, director of the NeuroDevelopmental Science Center at Akron Children's Hospital in Ohio.

"Children are very sensitive about the way they look and the way they act, and when a kid has a serious medical condition it amplifies the situation. Many teenagers won't go to a party if they have a pimple on their face—imagine being in a wheelchair, or having seizures, or not having hair," he says. "A specialized camp may be the first time these children meet others in a similar situation."

SPECIALIZED PROGRAMS

While a standard camp may not be able to meet the needs of children with complicated medical conditions, hundreds of specialized ones can, Dr. Cohen says. "A medical team is on site, if necessary, but the child can still have a camping experience. The kids shed themselves of their parents, which is healthy, and are among other kids with the same condition. They play and learn together. They even have fights together. They develop a greater sense of independence and self-confidence. The vast majority of these kids can't wait to go back every summer."

To help you choose the right one for your child, we spoke with camp directors and parents from four representative sets of camps for kids with neuromuscular conditions, seizure disorders, brain tumors, and cognitive delays.



IN THE SWIM At Muscular Dystrophy Association camps, counselors are trained to work with children with muscle diseases.

MUSCULAR DYSTROPHY ASSOCIATION CAMPS

- ▶ **NEUROMUSCULAR DISORDERS**
- ▶ **Locations:** National
- ▶ **Duration:** One week
- ▶ **Special requirements:** Open to children ages 6-17 who have any of the neuromuscular diseases in MDA's program
- ▶ **Cost:** Free
- ▶ **More information:** bit.ly/MDA-Camps

The Muscular Dystrophy Association (MDA) runs one of the oldest camping programs for children with special needs, dating back to 1955. As of 2016, the program serves about 3,800 children every summer in nearly 75 weeklong summer camps staffed by 4,000 trained volunteers and 400 medical staff, most of whom have specific training and expertise in neuromuscular conditions, according to Carolyn Drummond, national director of the MDA. Every child attends MDA camps at no charge.

FRIENDS FOR LIFE

"It really is a life-changing experience for our campers," Drummond says. "They may have limited muscle strength and mobility, but they can still participate in adventures like horseback riding, swimming, fishing, and hiking. Even more important, they develop lifelong friendships with kids who understand what they're going through."

SATISFIED CAMPERS

In a recent MDA survey, Drummond says that 97 percent of parents agreed that camp increased their child's confidence, 90 percent agreed that it motivated their child to try new things, and 81 percent agreed that it improved how their child asks for help with personal care. "Camp builds confidence and independence for all children, but it's particularly important for our kids," Drummond says. "It's camping with a purpose. These children are living longer and stronger and going off to college, which wasn't really happening too long ago, and we're helping them get ready by taking them out of their comfort zones a little. Meanwhile, all the children know is that they're having a great time!"

BUILDING INDEPENDENCE

Indianapolis mom Karen Russo sent her children, Natalie and JC, both of whom have spinal muscular atrophy type 2, to MDA camp when they each turned 6. Now in their 20s, both have graduated from college and live on their own; JC got married in 2016. Russo credits much of this independence to their experiences at camp. "Over 10 or 11 years of summer camp, my kids were exposed to different caregivers, and when they became young adults they weren't afraid to be on their own," she says.

Anxious parents can stay with their kids during the first day at MDA camp, Russo says. "You meet the counselor and go over all the information about your child's disability with him or her directly: strengths and weaknesses, what he or she can and can't do. You're not leaving a 6-year-old kid to explain to someone



SAFE FUN At Camp Candlelight, children with seizure disorders enjoy camp activities while also learning how to manage their conditions.

new how to move or shower or toilet them. By the end of that day, you're comfortable leaving your child in these people's care. You know your kids can finally do the things they see other kids doing, but in a safe, controlled environment."

CAMP CANDLELIGHT

- ▶ **SEIZURE DISORDERS**
- ▶ **Locations:** Prescott, AZ; multiple Epilepsy Foundation affiliate camps nationwide
- ▶ **Duration:** One week
- ▶ **Special requirements:** Open to all children with epilepsy or seizure disorders ages 8-17; must be able to feed, bathe, dress, and toilet with minimal assistance
- ▶ **Cost:** Free
- ▶ **More information:** bit.ly/Epilepsy-Camp-Candlelight

Karen Bayless Feldman wishes she wasn't a helicopter parent, but she has good reason to be. Her son, Brennan, had his first seizure at age 8, and despite surgery to remove a benign tumor called a protoplasmic astrocytoma, he continued

to have a persistent seizure disorder. "He would stop breathing during seizures sometimes. It could get really bad," says Feldman. "So I didn't trust anyone with him. If he went on school field trips I had to chaperone. He went back to sleeping in our room."

Then Feldman and her husband heard about Camp Candlelight, a one-week camp sponsored by the Epilepsy Foundation of Arizona in the cool pines near Prescott—one of dozens nationwide run by local Epilepsy Foundation affiliates—and decided to take the plunge and let Brennan go. "As a little kid, he didn't understand why we were so paranoid and worried. We thought it would be good for him to have a chance to make friends who understood what he was going through, what it's like to have epilepsy when no one else in your class has it."

Feldman admits she was worried. "I remember thinking, 'Oh my God, some of these beds are bunk beds. If I tell Brennan I don't want him on the top bunk, he's going to be on the top.' I'm glad now that I didn't really know all the things they would do, like horseback riding and rock climbing."

TALKS WITH DOCS

In addition to all those typical summer camp activities, Camp Candlelight hosts a series of "doc talks" CONTINUED ON PAGE 29

COURTESY EPILEPSY FOUNDATION OF ARIZONA

A FAMILY AFFAIR The Brain Tumor Family Camp takes place over a weekend and allows parents and children to share stories and advice.



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with its team of pediatric epileptologists—two doctors and two to four nurses are always on site—about topics like different types of seizures, medications, and how to deal with bullying and other social issues, says executive director Suzanne Matsu-mori. “Many parents have difficulty letting go for a week. We tell them that their child is safer here than at school! But we’re not holding hands. One of our goals is to teach independence.”

LESSONS LEARNED

Brennan returned from camp with a host of new friends—and a new attitude to pass on to his parents. “I asked him what the people at camp did when someone had a seizure, and he told me they’d sit with them, talk to them, rub their back and tell them everything’s going to be okay,” Feldman recalls. “I thought that sounded a lot better than what I did, which was freaking out and crying and calling the paramedics and taking him to the ER. So after that, I just tried to channel camp. If he had a seizure, I’d take a deep breath, sit with him calmly, rub his back and tell him everything would be okay. I thought, ‘Wow, he went to camp for a week, and it made us all better.’”

When Brennan’s seizures increased, the camp knew to assign a counselor specifically to him so he wouldn’t be alone. “They knew when a kid needed more freedom and when he needed someone with him all the time, but they did it in a way that didn’t make him feel smothered.” When Brennan was hospitalized for brain surgery at age 16, the majority of visits were from kids he’d grown up with at camp. “He didn’t have to explain anything to them. They knew what was going on.”

Now 19, Brennan will be doing his second stint as a counselor at Camp Candlelight this summer. “He wouldn’t miss it for the world,” Feldman says. “The only time he missed camp was when it coincided with his high school graduation. He comes home from camp and he feels good about life.”

COURTESY ONE STEP CAMP

ONE STEP CAMP

- ▶ **BRAIN TUMORS**
- ▶ **Locations:** Lake Geneva, WI; other camps throughout the country
- ▶ **Duration:** Weekend; other One Step camps range from weekend to weeklong
- ▶ **Special requirements:** Open to all families who have a child with a brain tumor ages 19 and under
- ▶ **Cost:** Free
- ▶ **More information:** bit.ly/OneStepCamp

Children’s Oncology Services, Inc., based in Chicago, runs about a dozen different One Step camp programs for kids with cancer, including a dude ranch, summer camp, winter camp, and ski camp. One of their most specialized is the Brain Tumor Family Camp, a weekend program near Lake Geneva, WI, that includes not only the child, but parents and siblings too. “When a child has a brain tumor, it’s a family diagnosis,” says Jeff Infusino, president of Children’s Oncology Services, Inc. “This camp allows the kids to socialize with each other, talk about how they take their medicine, and what it’s like at school. It also allows parents to see how other families face their situation and ask questions. They build relationships with other parents who understand the journey they’re on.”

WEEKEND CONNECTION

Families arrive on a Friday evening, and parents and kids meet and connect with each other through games and activities. Saturday is full of crafts and outdoor activities for parents and kids, together and separately. Later that night, parents network with each other while counselors take the kids off to play games. On Sunday parents and kids watch a slideshow and videos that recap



BUDDY SYSTEM Camp Ramah camps integrate children with disabilities such as Down syndrome, autism, and developmental disorders with their neurotypical peers for a diverse summer camp experience.



the weekend's experiences, as they eagerly trade phone numbers, email addresses, and Facebook links. The camp also has its own online social group, which helps families, who come from a five-state area in the Midwest, to maintain connections with each other throughout the year.

BRANCHING OUT

"Attendees become like second families," says Infusino. "They call each other for advice, rely on each other in tough situations, even go on vacations together." After a weekend at the camp, parents often feel more comfortable sending their children on their own to one of One Step's other sleepaway camps—all of which are staffed with full volunteer teams from major hospitals who can treat children with complex conditions.

That's what happened with Peggy Rider, now 18, who began attending Brain Tumor Family Camp with her mom, Mary, at age 13. Diagnosed with a benign brain tumor at age 6, Peggy "falls through the cracks," her mom says.

"They resected her tumor when she was 7, and we thought everything was fine, but it wasn't. She lost half her vision and had some cognitive problems, and four years later she started having seizures, which led to more cognitive problems," Mary explains. "Kids with benign brain tumors aren't 'cancer kids' per se, but they have enormous issues just the same."

The family had tried other camps and support groups, but found they didn't fit. "We were a square peg in a round hole," says Mary. She thought Brain Tumor Family Camp would be another mismatch, but Mary and Peggy agreed to give it a try.

HOME AWAY FROM HOME

"I didn't see how she would fit in, but after 24 hours there, it was like being home," Mary says. "The kids go off to age-appropriate activities, and parents sit in breakout sessions where we can talk with other parents without the children overhearing. It's the only group of people I can talk to, and they truly un-

derstand. It doesn't matter if your child's tumor is malignant or benign or what kind of treatment he or she has had, we're all there for the same reason: to support each other and learn and take away as much as we can."

Mary and Peggy return to Brain Tumor Family Camp every year, and Peggy has since attended the dude ranch, the regular summer camp, and a winter camp that features skiing, snowboarding, and tobogganing. "Camp was the first time Peggy has really had friends," says her mom. "Her medical experience segregated her from most kids her age. When she was back in school, they put her in this bubble wrap and didn't let her be a kid. At camp, no one's looking at her funny and asking her questions. It was the first time she wasn't embarrassed for others to see her scar. She's gained self-confidence and the understanding that she's likeable and capable of having friends."

CAMP RAMAH TIKVAH PROGRAM

- ▶ **COGNITIVE DELAYS**
- ▶ **Locations:** Palmer, MA, and multiple locations nationwide
- ▶ **Duration:** Two to six weeks
- ▶ **Special requirements:** Different age and special needs requirements by program; all programs emphasize Jewish life and traditions
- ▶ **Cost:** Varies based on duration and location; typically ranges between \$2,300 and \$8,500, with some financial aid offered
- ▶ **More information:** CampRamah.org

Most camps for kids with neurologic conditions are freestanding, specialized camps focused on one condition alone. At some other camps, a specialized program runs alongside a regular summer camp.

That's how it works at Camp Ramah, a network of nine Jewish summer camps that is a pioneer in the inclusion of campers with

COURTESY RAMAH TIKVAH

“Every parent has said to us after their first year, ‘I can’t believe the change in my child. She’s become so much more independent.’”

—CARRIE CHALUP

disabilities. Its national Ramah Tikvah program has locations at Ramah camps throughout the country. For example, the Tikvah program at Camp Ramah Darom in Clayton, GA, serves children with autism spectrum disorder, social anxiety, pervasive developmental disorder, and nonverbal learning disorders.

INTEGRATIVE CAMPING

“Each camp is a little bit different,” says Howard Blas, who directs the National Ramah Tikvah Network. “The one in New England is our oldest and largest and probably has the widest range of campers with disabilities. Some are on the autism spectrum, some have intellectual disabilities like Down syndrome or Williams syndrome, others have seizure disorders or cerebral palsy—we have campers with many different conditions.”

The Tikvah program runs alongside Ramah’s typical camp, and big chunks of the day happen together, like mealtimes and campfire get-togethers. Some campers with disabilities participate in Ramah’s inclusion program, taking part fully in the typical camp experience, while others spend part of their days with Tikvah and the rest in the typical program. “We are really able to customize and individualize the program; there are many different ways through camp,” Blas says.

Long Island parents Carrie and Alan Chalup first sent their daughter Alexa, now 20, to Tikvah at Camp Ramah in western Massachusetts when she was 9. The middle child of three siblings, Alexa, who has Down syndrome, watched her older brother go off to sleepaway camp and assumed her turn would come. The Chalups visited several other camps before finding Camp Ramah. “We went to visit, and she turned around and immediately said, ‘I want to go here!’ She didn’t say that about any of the other camps,” says Alan. “Ramah integrates neurotypical peers and peers with special needs really well, and everyone respects everyone else.”

FOREVER CAMPER

Alexa began at Camp Ramah as an inclusion camper in a cabin with neurotypical kids, with special needs staff assigned to her. At 16, her parents transitioned her to Tikvah because participants in that program can stay at camp longer than their neurotypical peers who are “aging out.”

“There is quite a range of diagnoses at

ONLINE RESOURCES

ASPIRES (Asperger Syndrome Partners & Individuals Resources, Encouragement & Support) keeps a list of camps for kids and adults with a variety of disabilities at bit.ly/ASPIRE-Camps.

NeedyMeds, best known for helping people find discounts on prescription medications, has a searchable database of camps and retreats at bit.ly/NeedyMeds-Camps.

The Federation for Children with Special Needs maintains a camp directory at bit.ly/FCSN-Camps.

Camp Ramah,” says Carrie. “There are kids like Lexi who are more independent, can read and write, and just need more help with certain things, but also kids with more severe impairments—some have hearing problems, some are blind with neurologic impairments. The camp makes it work for everyone. We’ve referred many families there, and every parent has said to us after their first year, ‘I can’t believe the change in my child. She’s become so much more independent!’”

5 Ways to Find the Perfect Camp

- 1 Ask your child’s neurologist or the nurse or social worker in the neurology practice or at the nearest children’s hospital.**
- 2 If you know other families who have children with a similar condition, either in your area or somewhere else in the country, ask them for a recommendation.**
- 3 Reach out to national organizations representing your child’s condition.**
- 4 Post a message in online support groups you frequent.**
- 5 Search online for “camps for children with (name of condition).”**

BE PREPARED AND STAY IN TOUCH

Once you’ve sent your child to sleepaway camp, he or she will probably beg to go back the next year. And you can expect him or her to experience a bit of a letdown when coming home, Dr. Cohen cautions. “It’s back to the world as it exists, and there’s a loss. It’s important to keep fostering those camp friendships.”

In addition to the camps profiled here, there are literally hundreds, if not thousands, of other camps that serve children and young adults with neurologic needs, either in separate stand-alone camps or as part of an inclusion program. Whatever your child’s needs, there’s almost certainly a camp out there for you. “Don’t give up until you’ve found that perfect match,” Mary Rider says. “I was so ready to throw in the towel. You will eventually find the right camp!”

WEB EXTRA For important questions to ask a camp director, visit bit.ly/NN-Camps.