

## **Brainy Camps In A Nutshell**

Brainy Camps Association (BCA) of Children's National is a consortium of residential camps, family camps and programs for children with chronic health conditions. The conditions served include high functioning autism spectrum disorders, Tourette syndrome, neurofibromatosis, epilepsy, sickle cell anemia, type 1 diabetes, heart disorders, Down syndrome, hydrocephalus, and cerebral palsy. We also offer a series of cooking classes for families with children at risk for obesity, family camps for young children with type 1 diabetes, a transitions camp for young adults, online support groups, and leadership training. During the fall and winter, we train teens to serve as peer counselors, giving them the tools to provide support and reduce the social isolation experienced by children with chronic health conditions. Our camps are run in collaboration with many of the healthcare organizations connected to the conditions served. Transportation is available for many of our camps.

In 2009, Brainy Camps Association (BCA) became a subsidiary of Children's National Health System (CNHS) and was officially established as its own independent non-profit organization, partnering with organizations around the country that serve children with chronic health conditions and offering families much needed respite each summer. In 2012, realizing the opportunities available for training and hands-on experience, BCA was approved as an elective for the CNHS Pediatric Residency Program and medical students from George Washington University.

## **Where We Are Today**

Our program began over 23 years ago as a single residential camp serving a population of 23 children diagnosed with epilepsy, with 12 volunteers supervising their interactions. Today, we have a consortium of 12 residential camps, serving over 450 campers each summer with an interdisciplinary team of over 100 medical experts, professionals and students offering their time and knowledge to ensure camper safety and enjoyment. Our campers come from all over the US, Puerto Rico and Canada, with a smattering of campers from other countries in the world.

## **What Makes BCA Unique**

Healthcare in the United States is becoming much more community based. Hospitals are opening satellite offices and clinics in highly populated metropolitan areas, making it much more convenient for individuals and families to access care. Transitioning from hospital to community-based care is necessary if medical systems are to attract new patients and retain existing patients in this highly competitive market.

BCA is ahead of the game in that we have been offering community-based care for years, making the transition from hospital to community care seamless and easy for our campers and their families. In a residential camp setting, chronically ill children are followed by a medical team who can see, first hand, how their patients respond to the treatment being delivered and, if treatment needs to be changed, it can be done immediately.

In addition, since they are seen without their parents when at camp, young patients are given a unique opportunity to form their own personal relationships with their medical providers. They learn to become self-advocates and partners with their healthcare team, asking questions and offering ideas that otherwise might not be heard. Having their own voice is especially important

for children diagnosed with chronic health conditions as they will be dealing with their personal health concerns throughout their lives and must know how to advocate for themselves.

Preliminary results of research conducted with our camp populations over the last seven years shows that giving chronically ill children control over their healthcare increases their resiliency and has a positive impact on feelings of self-worth and expectations for the future.

## **Services Provided**

BCA works closely with medical experts in many healthcare specialties— including cardiology, endocrinology, hematology/oncology, neurology, genetics, pediatrics and physical medicine—to provide a seamless flow of care and improved health management in children with chronic health conditions. Our programs include condition specific camps for children and families, educational training of campers and staff, and therapeutic support for all. We commonly begin with an assessment of need conducted in hospital clinics and in the community, with the findings used to develop and design our camp programs and services. Our research over the past ten years supports the benefit of BCA's intervention model, with changes in our interventions reflecting our study findings and new developments in the field.

The primary goal of BCA camps and programs is to help youth with chronic health conditions live well and reach their potential. Our camp programs provide chronically ill children with an opportunity to meet peers, mentors and counselors with the same conditions and discover they are not alone in the world. Having experienced the loss of peers at much too young an age, they live with a keen awareness of their own vulnerability. The hurdles they face are many, including continuing medical care, over-protection by worried parents, stigmatization by peers and society, social isolation, and fear due to the unpredictability of their conditions. In the safe environment of camp, where the condition is shared and respect is the norm, individual boundaries are challenged and children begin to develop a sense of personal strength and self-worth.

For many families, attendance at our residential camps is the first time their children have the opportunity to be away from home for more than the length of a school day. Medical staff with expertise in the conditions served manage each camp, making parents feel safe to leave their children in our charge. Staff training and experience in caring for chronically ill children and our 2:1 camper-staff ratio further helps to allay parental concerns. For many, camp provides parents with their only opportunity to sleep through the night.

## **Our Camp Program**

BCA's residential camps offer a large variety of activities for campers to enjoy, giving them the opportunity to test their limits and try things they never have before. Educational seminars, led by our medical teams, increase knowledge and self-management skills and give campers an understanding of their conditions and a much needed sense of control. Support groups allow campers to express their feelings, learn to effectively disclose and discuss condition and age-related matters, helping them to develop skills and solutions to problems in a manner that elevates their self-esteem and increases their safety. Through these various means, the campers begin to identify their personal strengths, resources, and goals to better manage their conditions, gain a sense of mastery, and contribute to the community.

At BCA, campers are encouraged to express their feelings and practice ways to effectively discuss/disclose their conditions to peers, teachers and others. They know they can rise as leaders in the camp community and are encouraged to take this new-found sense of worth and strive for whatever they choose. They come to realize their disorders do not have to limit them from developing interests and dreams and, with the support of their camp family, they develop the confidence to reach for their goals.

Participation in BCA helps children understand their conditions, learn about their medications and the necessity of compliance, recognize triggers that exacerbate symptoms, identify the comorbidities of depression, anxiety and learning difficulties, and develop self-management skills. BCA participants come to understand the many factors that impact their health in order to live well with their conditions. For example, understanding the impact of exercise on insulin and counting carbohydrates are critical for effective diabetes management; identifying triggers that increase seizures—such as heat and the lack of sleep—can help children gain control of their seizures; avoiding positions that cause pain and possible issues with pacemakers is essential for children with heart conditions; and recognizing the impact of sudden temperature changes on sickle cell disease reduces the potential for pain and strokes.

Learning effective ways to manage one's condition and overcome barriers in order to reach goals and live well are priorities for BCA. Educational question-and-answer sessions encourage campers to voice their concerns and learn more about their conditions. Support groups, both formal and informal, promote self-awareness, self-advocacy and a new found sense of safety and support. Medication management four times a day and round-the-clock medical staff supervision promotes medical safety. The range of activities offered challenges each camper's physical and personal boundaries. Campers are encouraged to identify short and long-term goals, develop friendships and build support networks that go beyond the days of camp.

While children and teens are supported in gaining skills, knowledge, friendships, and having fun, they are also respected and appreciated as teachers and experts in the world of chronic health disorders. Being seen as the experts, youth become empowered while educating college, nursing and medical students, as well as the many allied health professionals who assist at our camps. The development of the interchangeable role of student and educator directly impacts the relationships these children create with their healthcare providers; thus, the potential for increasing effective communication and medical co-management of the condition greatly improves.

We would be remiss if we did not mention our Memorial Garden, created in honor of the more than 20 members of the BCA family lost over the past two decades. With its running fountain and peaceful surroundings, the garden provides a serene setting for campers to remember their lost friends and be reminded to live their lives to the fullest.

## **Teen Leadership Program for Counselors-in-Training (CITs)**

Brainy Camps Teen Leadership Program is designed for 16 and 17 year olds who are interested in becoming future counselors. Many are past campers who want to “pay it forward” by helping to guide younger children through the challenges that living with a chronic health condition present. The focus of our Leadership Training Program is to develop interpersonal and communication skills while gaining experience in planning, instructing and executing activities

for younger children. The techniques taught will help our CITs to successfully perform their roles as the up-and-coming camp leaders and prepare them to become advocates for themselves and others as they gain self-confidence and move on with their lives.

CITs receive hands-on experience working with campers while under the direct supervision of experienced counselors. They meet nightly with clinically trained professionals who provide group supervision and leadership training for the participants.

## **Peer Counseling Training**

As an extension of our Leadership Training Program, we added an online Peer Counseling Training Course to the services we provide. A select group of teens are chosen each year to participate in a seven-session training course to learn communication skills that will enable them to serve as mentors to other children with chronic health conditions. They are then paired with children and teens referred from the hospital clinics and community to act as mentors and guides, helping to ease any fear and confusion the referred children may be experiencing. All Peer Counselors receive ongoing support and supervision from BCA's clinical staff. They also attend a monthly online leadership group to maintain connection with the other Peer Counselors, obtain their support, and further improve their leadership skills. Finally, they are asked to serve as Teen Advisors on BCA's Professional Advisory Board, made up of our healthcare personnel who determine the medical procedures and protocols to be followed at camp.

## **Camp Next Step: Our transitions program for young adults**

Ten percent of young adults between the ages of 17 and 24 have difficulty making a smooth transition to adulthood. They face many barriers in trying to become successful and independent and are at risk for a number of negative outcomes, including unemployment, feelings of failure and an inability to make appropriate future-oriented decisions.

Our Next Step program is designed to assist young adults in overcoming their personal obstacles and make a successful transition to adulthood. Participants attend an overnight session that pinpoints their strengths and weaknesses in problem-solving, communications and interpersonal interactions. Under the direct supervision of experienced counselors, they are then paired with developmentally disabled individuals and serve as role models and mentors. Helping them to be productive and successful in this role results in enormous social and personal benefits for the young adult as well as the individuals with whom they are paired.

## **Financial Assistance For Families In Need**

Each year, approximately 55-60% of our campers are in need of scholarships to attend camp. Families must submit a scholarship request form with documentation showing income and expenses. We use the US DOHHS definition of low income families as our guideline for determining who receives funding. Those with incomes less than 200% of the federal poverty level (FPL) receive full scholarships. Those with incomes between 200% and 350% of the FPL receive partial scholarships.

## Research

Our research, which explores the impact of participation in condition specific camps on chronically ill children, began with a look at adaptive coping skills. We found that our condition specific camps encouraged independence, cooperation, socialization and responsibility and that return campers demonstrated greater benefits.

Next, we became interested in the role hope plays in the lives of chronically ill children. As hypothesized, initial study results suggest hope is an important factor in chronically ill children adapting to and accepting of their conditions.

Based on our findings with adaptive skills and hope, we became interested in resilience in chronically ill children. We conducted a study to look at symptom severity on quality of life and its impact on resilience. Not surprisingly, our research showed that children with chronic health conditions were less resilient than their healthy counterparts. Additionally, the more severe their symptoms, the lower their quality of life. We also found that, with our population, the more resilient the individual, the better their quality of life regardless of symptom severity— defined as learning difficulties, physical symptoms and behavioral issues. These findings resulted in our revising our research direction, tools and focus and helped us to reevaluate and alter our camp design.

Currently, we are in the process of analyzing the results of our research data, collected over the last seven years, that examines the impact of community cohesion—or peer-shared experience—on resilience. Over 1,000 children from our condition specific camps have participated in this study. The results of our research will be ready for publication in the near future.

With each of our research findings, we review and update our IRB (Internal Review Board) protocol, adapt our tools of assessment, and alter our camp design to incorporate our new understanding of what impacts chronically ill children and improve our delivery of care.

## Benefits of Participation

With the support of our professional staff and cohesion of our camp community, children who attend Brainy Camps become more available to learn, test their limits, develop skills, and connect with peers. Rather than live in fear, they gain a sense of hope and begin to explore a future filled with possibilities. With a strong network of peer support, growth is promoted, individuals are empowered, and leadership skills develop.

This positive change has a ripple effect that goes far beyond the confines of the camp community. The level of supervision provided allows campers the opportunity to challenge themselves, push beyond their limits of comfort, and try new things in a safe and supportive environment.

Over the years, many of our campers have gone on to work in a variety of helping professions including healthcare, education, and public service, with a desire to make a difference and positively impact the lives of others. They become leaders among their peers and advocates for themselves and others in the community. Their successes provide a model of courage for others and demonstrate that their conditions need not limit their choices or define who they are.

## **Camp Staff**

Each condition-specific camp is staffed 24 hours a day by physicians and nurses who are experts in the field. Additional professionals include a social worker, physical therapist and a psychologist, as well as other medical personnel who volunteer their time and expertise at the various camps. The counselors are carefully selected for their genuine interest in children and receive special training to deal with each unique population. Many have the identified condition and have gone through our Leadership Training Program to become role models for our campers.

Please contact us for more information.

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