

***Independence Day came early this year for those that attended the first ever summer camp for kids ages 7-14 diagnosed with 22q11.2 deletion syndrome.***

Dragonfly Forest Camp operates for six weeks each summer for children with special needs. This year, the 22q11.2 deletion syndrome was added to a schedule that already includes weeks for Autism, Hematology and Respiratory disorders. Camp is held at the breathtaking Westtown School, in West Chester, PA every summer. This breath taking campus is home to a boarding school during the non-summer months. But come summer time, let the fun begin! Through a very generous donation from the International 22q Foundation, a week long, overnight summer camp became a reality for 45 kids diagnosed with the 22q11.2 deletion at no charge to their families!

There is no question in my mind that this camp changed the lives of each and every one of these kids, it absolutely changed mine. Many of whom had never spent a night away from home. As with any new venture, there are always the pioneers who travel the uncharted waters and forge a path for those behind them. I am proud to write that I met a room full of pioneers; all parents that on the first night gathered together in the hotel lobby four miles away from camp. While the mood was indeed upbeat I sensed a collective wondering...

“Did we do the right thing?”

“Did we really just leave our special needs child at summer camp?”

“Maybe we should have waited until next year?”

It wasn't until that first update was twittered from camp counselors that the mood eased a bit and when the first pictures leaked out to the internet, those nervous musings all but melted away and the vacations actually began! As Director of Development for The Dempster Family Foundation I was lucky to observe this incredible Camp. As soon as you step onto the campus, there is a breath of “this place is good” that washes over you. Take a few steps and you're bound to cross the path of the “green group” off to the ropes course, the “yellow group” shuffling to arts & crafts, or the “red group” wrapped in colorful towels, headed to the giant indoor pool. Big deep breath..... this place is good!

If, you're wondering how a special needs camp is different from a “normal” camp... It isn't... much. The only differences I observed were; a very high counselor to camper ratio, more medical staff, and sometimes a little extra explaining of an activity. The rest was exactly what you'd expect, kids having old- fashion fun. Laughing, being loud, trying new things in the presence of others trying new things; which let's face it, tend to make “trying new things” easier! Girls whispering to each other about a crush on a boy, boys running around oblivious to their suitors, squirting each other with water guns! Some kids sticking right by their counselor's side and others asserting their new found freedom amongst friends! It was a spectacular sight to behold. I am forever changed for having spent a week with these kids in West Chester, PA.

It shouldn't go without mention that Fred Weiner, Executive Director deserves special recognition for spending much of each year readying the supplies, minding the business, and refilling the coffers to run this amazing camp. Raising these funds is no small task and should not go unnoticed. The incredible efforts of Sylvia Van Meerten and Scott Arizala, Camp Directors, are yet another impressive attribute to Camp Dragonfly Forest. I think it's fair to say that they are the beating heart of this camp. Both of them

free spirits with never ending supplies of energy and the ability to train the 75+ counselors in the unique methods necessary to provide an exceptional experience for campers each week. In addition to preparing the camps very intricate schedule, they also manage the creative activities/programs that keep both the kids and counselors coming back, year after year!

The Dempster Foundation in partnership with Elwyn Genetics and the great Brenda Finucane was able to coordinate a "Family Activity Week" for the families of the campers. This included several "listen and learn" discussion sessions for moms and dads to share their individual experiences dealing with 22q. Being surrounded by people who "know what its like" as one mother said "gives us all incredible peace of mind, even if it's only for a short time". as well as a welcome reception, and trip to Hershey Park!

Elwyn Genetics also brought their innovative Sibshops Program; a workshop created for the siblings of children with special needs. *Sibshops* offer brothers and sisters the opportunity to meet and interact with others who know what it is like to have a sibling with a developmental disability. *Sibshops* include a lively mixture of games, discussion, and guest speakers targeted for siblings 8-12 years of age. Having fun is the highest priority at these workshops. After about 24 hours, the siblings had taken over the hotel and were comfortable, relaxed and pretty much running the show!

"Parent Activity" week provided the opportunity for The Dempster Foundation to launch the "Parent Empowerment Program"; a coordinated effort to rally the 22q Community together for the end goal of driving awareness of this little known but common genetic syndrome. The Parent Empowerment Program's goal is to gain the commitment of each and every affected family to take an active role in driving awareness or raising funds within their individual communities. Acceptance of the social responsibility by the current parents and children, will hopefully allow those that follow the ability to navigate the 22q road with greater ease. For not one parent, doctor, teacher, or foundation can shoulder this responsibility, but together we can move mountains. The response from parents was overwhelming and a clear example that we are on the right path.

Executive Director, Fred Weiner proudly took the time to share with me some of the written feedback from both parents and campers at the conclusion of the program. In closing, I'd like to quote one young camper from the 2010 Dragonfly Forest Camp session:

**"Dragonfly Forest is a chance of a lifetime...**

**And, I love chances of a lifetime"**

**-Unknown Dragonfly Forest Camper**

Please support the organizations that aid the lives of children and families affected by the 22q11.2 deletions syndrome. Your donations of time, effort and/or funds can make a genuine difference within the 22q community.

Most Sincerely,  
Michelle Breedlove Sells  
Director of Development  
The Dempster Family Foundation