



# The Blue Ribbon Tribune

Official Newsletter of 1p36 Deletion Support & Awareness  
Spring 2011

Inside this issue: A report on our visit to the American College of Medical Genetics Conference, exciting upcoming events, fundraising excitement, the 1p36 DSA member survey, apps for special needs kids and more! Here's a complete index:

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## 1p36 DSA Board Members Attend ACMG Conference in Vancouver, British Columbia

By Carrie Daggett



In March, Ken Shirtcliff, 1p36 DSA's board president, and I attended the ACMG (American College of Medical Genetics) Conference in Vancouver Canada. The conference brings together professionals in the clinical genetics field as well as researchers

and patient advocates for education, networking and a chance to share research and advances in the practical application of genetics. Our primary goal in attending the conference was to learn how 1p36 DSA might collaborate with the medical genetics community to increase awareness of 1p36 Deletion Syndrome and to insure that accurate and relevant information about the syndrome is communicated to families. 1p36 DSA believes that greater awareness will lead to early and accurate diagnosis

which could mean better outcomes for the medical conditions often associated with the syndrome.

We were able to speak with other members of similar patient advocacy groups to own as well as learn about exciting advances in the genetic testing field that will hopefully bring us closer to the goal of no child with 1p36 Deletion Syndrome going undiagnosed. A highlight of the conference for us was the chance to sit down with Dr. Lisa Shaffer, PhD, Cofounder and current President of Signature Genomics who has published multiple studies on 1p36 Deletion Syndrome and has consistently given us her valuable insight and support.

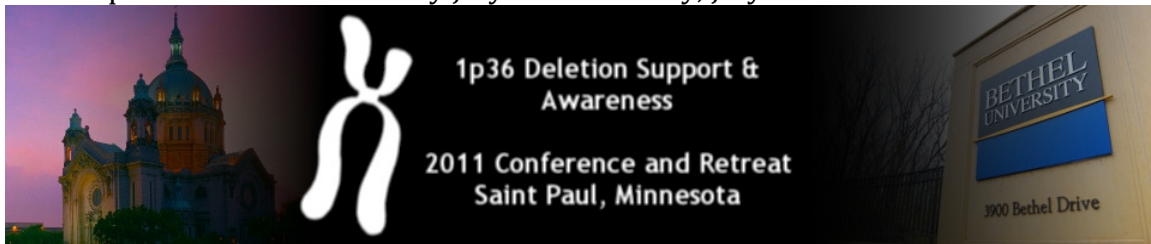
I was also very fortunate to attend the conference through a scholarship offered by Genetic Alliance's Advocate Partnership Program. The program's

intent is to encourage collaborations between members of the patient advocacy community and health professionals. Participants are required to attend daily sessions during which key members of the ACMG professional community are available to answer questions and to discuss genetic related concepts and ideas. It was an invaluable experience. I came away inspired by the other Advocate Partners and very excited about the future of 1p36 DSA and how we can better work toward improving the lives of individuals with 1p36 Deletion Syndrome.

For more information on the American College of Medical Genetics visit their website at [www.acmg.net](http://www.acmg.net). And to learn more about Genetic Alliance you can visit their website at [www.geneticalliance.org](http://www.geneticalliance.org).

## Upcoming Events

**5th Annual 1p36 Deletion Support & Awareness Family Conference & Retreat**  
Minneapolis-St. Paul – Thursday July 14<sup>th</sup> – Sunday, July 17<sup>th</sup>



The 5<sup>th</sup> Annual 1p36 Deletion Support & Awareness Conference and retreat will be held this summer in Minneapolis-St. Paul on July 14<sup>th</sup> through the 17<sup>th</sup>. The campus of Bethel University will provide a relaxed and friendly environment to learn and share with other families.

The schedule and speaker list for this summer's conference has been posted and the reservation system is now open. But don't miss out, reservations must be in by June 15<sup>th</sup>. To learn more about the conference and make your

reservation,

visit

[1p36dsa.org/2011conf](http://1p36dsa.org/2011conf).

### **UK & Ireland Summer Event – 1p36 Families Weekend**

Southampton, UK – Friday August 5<sup>th</sup> – 6<sup>th</sup> 2011

The 1<sup>st</sup> Annual Families Weekend will be held this summer in August in Southampton, England. It will include a family party night, Trip to Paultons Park, Dad's curry night and Farewell Drinks. If you are interested in attending the event, please visit [The 1p36 Family](http://The1p36Family) website or email Jenny Burnage [j.burnage@sky.com](mailto:j.burnage@sky.com) for information pack and booking form.

Please note this is a non-profit event arranged by parents. A price will apply to each event to cover the cost of food, drink, entrance tickets and other expenses. More details will be on the booking form. Some events have limited spaces and will be allocated on a first come first served basis.

### **1p36 Gathering, Picnic and Meet & Greet**

Indiana – July 10th, 2011

A gathering, picnic and meet & greet will be held Sunday July 10<sup>th</sup> 10:00am – 1:00pm at [Clifty Falls State Park](#) in Madison, Indiana. If you are

interested in attending, please send an email to [robinrjabigail@yahoo.com](mailto:robinrjabigail@yahoo.com) for more information.

### **Picnic & Play**

Delaware – June 4<sup>th</sup>, 2011



A picnic and play event is being planned for June 4<sup>th</sup> at the [Can-Do Playground](#) at the Alapocas Run State Park in Wilmington, DE. The **Can-Do Playground** is a unique play environment where children of all

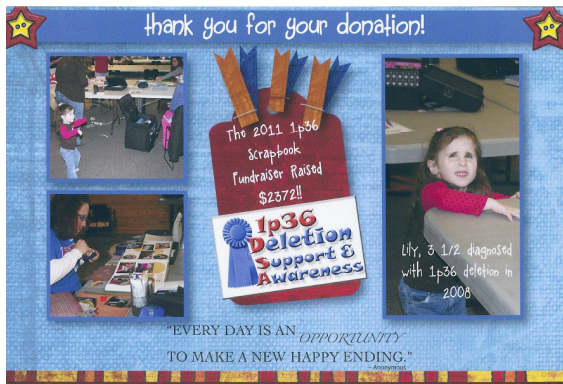
abilities can explore, create, dream and just plain have fun. It is a place where every child “can do” it! The group is renting the pavilion and having lunch together. For information on the event, please send an email to [genahmichelle@gmail.com](mailto:genahmichelle@gmail.com).

Are you planning an event or did you get together with another family? Include the information in our next newsletter. Send your information to [info@1p36dsa.org](mailto:info@1p36dsa.org).

## Fund Raising Events

### 3<sup>rd</sup> Annual Scrapbook Event

Jason & Julie Friedman – Parents of Lily



The 3<sup>rd</sup> annual 1p36 Scrapbook Fundraiser was held on January 29th. The event raised \$2250. This puts the total fundraising over the last three years to at almost \$10,000!!

### 2<sup>nd</sup> Annual Dodgeball Tournament

Beau & Sherry Culvahouse – Parents of Kaylee



The 2nd annual 1p36 Dodgeball Tournament was a huge success!! 12 teams consisting of 6 people participated at Dewey's Beer Garden in Corpus Christi, Texas on March 12. These 12 teams sweated it out to support 1p36 Deletion Support & Awareness and had fun doing it. Dave, the owner of Dewey's Bar, and his staff helped plan the entire event and did a marvelous job. They got people

pumped up and motivated, let them know why being involved in the fight against 1p36 deletion syndrome is important and pushed people to help out with our cause that we hold so dear to our hearts. There was an incredible positive energy throughout the day. Overall, we had a great turnout considering it was the start of spring break. There were also many who came out just to support Kaylee and 1p36 DSA.

The day started off with an escort by the Patriot Guards and 2 other motorcyclist clubs. We were greeted and escorted by 21 motorcycles from our home to Dewey's Beer Garden. It was the best 20 minutes ever. It was an experience that we won't ever forget. Our babies were treated like

celebrity. We rode in a limo and had 6 motorcycles in front of us and the rest rode behind us. It was an exhilarating feeling to hear the roar of all those motorcycles. It brought giggles and smiles to Kaylee's face. It was a truly a memorable and heartfelt moment! Everyone who participated had such big hearts with one goal in mind which was to support 1p36 DSA. They all wanted to do it again next year. Can't wait to see them play dodgeball again. It was fun to watch them play in their leather attire and helmets....what a sight to see!

There were lots of support from several local businesses. HEB, a grocery store chain, donated \$1,000 which was our 1st place cash prize. Whataburger donated \$500 and the Philomeno family in Seattle donated a whopping \$1500 dollars. Judy and her husband hosted a booth of their delicious snow cones. After a fun filled day, everyone was so grateful for the yummy refreshments. Baby Eric's family spent hours and hours cooking briskets. They made mouth watering pulled brisket sandwiches! It was a great hit and they were to die for! We also had yummy potato salad and beans as our sides. We sold many plates for \$5.00 each. Many volunteers helped serve barbeque plates. They made the whole process go smoothly. We couldn't have pulled off the day without their dedication and hard work.

We also had a great turnout at the silent auction. Many people donated many items such as the IceRay's court side suite, our local hockey team, a guitar made out of a cigar box, Goldsgym 3 month membership, art

decor, beer coolers and chairs, gift certificates...these are just a few wonderful items that were donated. We were also on hand with information and were so appreciative of all the many questions and the sincere interest in learning more about 1p36 deletion syndrome. It always motivates us when new people have been reached and real awareness has taken place. The Crush girls helped us reach many people by interviewing Eric's mom, Amanda, and myself via their web cam. Also, Steven with ESPN brought so much needed awareness to our community. Beau was so excited to be on their ESPN show. He did a wonderful job...he didn't even sound nervous! We were also thankful for Channel 3 for covering our story prior to our event and channel 6 news for covering the day of our event. Media coverage was challenging since it was a busy weekend filled with spring break events.

I would like to thank my husband Beau for creating this wonderful event. He poured his love, dedication, and hard work into this tournament and it definitely showed. I know he will continue to do it again in a heart beat just to make a difference in one person's life. Big thanks to Dave and his staff at Dewey's Beer Gardens, Jim & Terri Philomeno, Alisa my sister, Akiko my mother, Whataburger, HEB, The Crushgirls, baby Eric's family, all of our friends and family. Thank you for making a difference! And thank you for believing in and supporting what we are doing with 1p36 DSA!

Once again we are humbled with everyone's support and generosity.

Thank you everyone once again for coming out in force and making a difference in 1p36 DSA. We are so, so

blown away that over \$5,500 was raised!!! So AWESOME!!!

### **BD 2010 Henry P. Becton Award Volunteer Impact Award**

Karen Bess – Mother of Aiden



[BD](#) associates and retirees share a long and proud history of contributing their time and talents to help make a difference in the lives of people around the world. For more than 114 years, they have volunteered to help others in numerous ways that reflect their creativity, diversity and talents. The Henry P. Becton Volunteer Impact Awards Program honors the late BD Director Henry P. Becton, Sr.'s lifelong commitment to community and BD's legacy of community service. The program recognizes the outstanding philanthropic efforts of BD associates and retirees by making financial contributions in the winners' names to the organizations for which they volunteer. This year, BD will award grants to 19 nonprofit organizations

around the world as a result of the Volunteer Impact Awards.

The BD associates and retirees honored for their efforts during 2010 devoted their personal time and talents to helping others. They include individual volunteers as well as teams of associates and retirees at BD locations around the world. We applaud them all and honor the organizations they serve.

#### **Karen Bess**

BD Corporate  
Franklin Lakes, NJ

#### **[1p36 Deletion Support & Awareness](#)**

“We provide support and education to caregivers and families dealing with a diagnosis of 1p36 Deletion Syndrome. We also increase awareness about the syndrome in the public and medical communities. Having the opportunity to share with other families dealing with the same situation and exchanging information is extremely important.”

*Karen Bess*

“The volunteer work I do for 1p36 Deletion Support & Awareness is personally important because my son was diagnosed with the syndrome in 2007,” said Karen. “It was discouraging to find how little information was available.” Karen

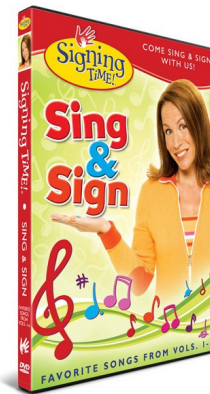
joined with five others to create a nonprofit organization that would provide support and education to families and increase awareness in the public and medical community of chromosome 1p36 abnormalities. In addition to serving as treasurer, Karen manages the organization's website, [www.1p36dsa.org](http://www.1p36dsa.org). The website

provides multiple ways to learn about the syndrome and links to articles and websites with additional information. "The site is visited by caregivers, therapists and doctors," said Karen. "It is a place to share information, ask questions and provide a sense of community."

**Do you have a fund raising idea to help raise funds for 1p36 DSA? Please send an email to [info@1p36dsa.org](mailto:info@1p36dsa.org).**

## 1p36 DSA Membership Survey

1p36 Deletion Support & Awareness is creating a membership database. Please complete one registration for each individual with 1p36 Deletion Syndrome. Everyone who fills out the 1p36 DSA Membership Survey in the **month of May** will be entered to win one of 3 Signing Time Sing & Sign DVDs\*.



[Complete Membership Survey](#)

\*Winners will be randomly drawn in June from individuals who complete the membership survey between 5/1/2011-5/31/2011. 1p36 DSA Board members are not eligible.

## iPhone / iPad Apps

by Karen Bess – Mother to Aiden

Did you just get an iPhone or iPad. Now what apps should you get? Check out these great resources.

### Babies With iPads

[babieswithipads.blogspot.com](http://babieswithipads.blogspot.com) or search Facebook for: Babies with ipads

This site is designed to document infants / toddlers with disabilities using an iPad to promote their

development. It shows how this new technology can help children with disabilities develop their communication, play, pre-literacy, cognitive, visual / auditory and motor skills. The facebook site is constantly being updated with new and free app suggestions.

### AAC Apps



[spectronicsinoz.com/article/iphoneipad-apps-for-aac](http://spectronicsinoz.com/article/iphoneipad-apps-for-aac)

A complete list of AAC ( Augmentative and alternative communication ) apps. Includes cost, apps with pictures, apps with text to speech and ratings.

### **Apps for Children with Special Needs**

[a4cwsn.com](http://a4cwsn.com) or search Facebook for: A4cwsn

Provides demos of apps for children with special needs so you can view before you buy. Great reviews and videos.

### **Moms With Apps**

[momswithapps.com](http://momswithapps.com) or search Facebook for: momswithapps

Moms With Apps is a collaborative group of family-friendly developers seeking to promote quality apps for kids and families. Most of our membership is comprised of parents who have launched their own apps on the App Store, have their own access to iTunes Connect, and have the time and inclination to share best practices with other developers at the founder's level.

### **Lillie's Pad**

[lilliespad.com](http://lilliespad.com) or Search Facebook for: Lillies Pad

The mission of this site is to be an up-to-date resource for everything special needs related to the iPad and the iPhone. Whether it be apps, app giveaways, videos, music, news stories, accessories, links, helpful hints, etc. My hope is to have this site be a trusted resource for the special needs community.

### **Special Needs Apps for Kids**

[snapps4kids.com](http://snapps4kids.com) or search Facebook for: Special Needs Apps for Kids

SNApps4Kids is a community of parents, therapists, doctors, and teachers who share information on how we are using the iPad, iPhone and iPod Touch with children who have special needs. We have found these mobile devices to provide accessibility for children who may have been previously disengaged from the world because of challenging language, motor, or other developmental delays.

Given the rising number of apps on the market and the diverse skills of children with special needs, parents have found each other to be one of the best resources for choosing apps to enhance everyday life for our children.

While our group is primarily parent-driven, our efforts are naturally collaborative with the people who help our children develop particular skills — therapists and educators.

**Do you use an app that you would like to share? Send an email to [info@1p36dsa.org](mailto:info@1p36dsa.org) and we will include it in our next newsletter.**