



1p36Deletion

SUPPORT & AWARENESS

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President's Message

On behalf of the 1p36 Deletion Support & Awareness Board of trustees, I hope everyone has had a wonderful summer. As we get back into the routine of the school year I wanted to let you know how the summer has gone for our organization and also some of the things we are working on.

This year marked the fifth year we have had an annual conference and this year it was held July 14-17th in St. Paul, Minnesota. It was a wonderful time to spend learning more about 1p36 Deletion Syndrome but also spending time with our 1p36 family and friends. Dr. Robert Hopkins from Cincinnati Children's Hospital was our keynote speaker and I believe he is going to be a valuable medical and scientific resource for our organization.

We also formally unveiled our new logo. See the announcement below:

1p36 Deletion Support & Awareness is proud to unveil a brand new logo! Starting with the 2011 conference and into the coming months, you'll find a dynamic new look for our blog, Website, Facebook page and publications. The purpose of the new logo is to create a 1p36 "brand" that will serve to give our organization a modern and unified identity. One that, we hope, will become as synonymous with 1p36 Deletion Syndrome, as the pink ribbon is

with breast cancer awareness and the puzzle piece is with autism. The logo features the first chromosome from 1p36 Deletion Syndrome in the shape of two people. They stand side by side, hands raised together in solidarity, just like our 1p36 family stands together supporting each other. They are similar but not exactly alike just as individuals with 1p36 Deletion Syndrome share many characteristics but are still unique. The missing bands on each arm represent the missing genetic material that has brought us all together. The colors are vibrant and eye catching and stand out on the web, print and other forms of media. After careful consideration, the board of 1p36 Deletion Support & Awareness feels that this new logo will form a fresh "brand identity" which will serve to make 1p36 Deletion Support & Awareness stand out in the realm of nonprofit organizations.

With the new logo we have also created a 1p36 DSA Store where you can buy many different clothing items with the new 1p36 Deletion Support & Awareness logo. \$2.00 from every item goes to help support 1p36 DSA. Just go to

www.1p36.spreadshirt.com. Check back often because we hope to add new items over time. We are also in the process of creating and designing a new 1p36 DSA website. It will have more information, easier navigation and be the place to go for all things 1p36 Deletion Syndrome. It will also be the home of the 1p36 DSA blog. We are working on an informational brochure similar to the one from Cincinnati Children's Hospital as well as forming a scientific advisory board to make sure that all the information that we put on the new website will be as accurate and scientifically sound as possible.

We are always looking for people who want to get involved and share their specific talents. Whether it be hosting a fundraiser or serving on a committee, we want you to let us know how you would like to help. You can also let me know if there are things you want us to make sure we

include in the new website. Just e-mail me at k.shirtcliff@1p36dsa.org.

Ken Shirtcliff
President, 1p36 Deletion Support & Awareness

2011 Annual Conference A Huge Success



The annual 1p36 DSA Conference took place this July in St. Paul Minnesota and was a great success! Twenty seven families attended the 2 ½ day conference that proved to be both a great time for families to connect as well as informative and educational. This year the conference was organized a little differently than those in the past with families staying together in dorm rooms on the beautiful campus of Bethel University. Families were able to have all their meals together in the college cafeteria. All the conference events took place in the college's conference facilities including

a large auditorium known as the Underground where most of the speaker events were conducted. Here is a short play by play summary of the weekend's events.

The weekend kicked off with a welcome from the conference organizer Beth Hegney in the Underground and a slide show showcase of children and adults with 1p36 Deletion Syndrome. Then Heather Antoine led everyone in a few fun, get-to-know-you games that made everyone laugh and helped to break the tension of meeting each other for the first time. Later that evening, there was a bonfire near the lake for families to visit and get to know each other better.



Friday morning began with an emotional and inspiring talk from Barbara Gill, author of [Changed by a Child](#). Barbara read from her book and spoke about topics such as Dreams, Rage, Potential, Fatigue, and Hope which are the titles to the different chapters. Any parent of a special needs child would benefit from Barbara's insightful thoughts and glimpses into the complexities that she herself experienced with her son who was born with Down Syndrome. As a wonderful surprise, Barbara gave a copy of her book to 10 lucky families chosen through a drawing of names.

Carolyn Allshouse, Executive Director of Family Voices of Minnesota, spoke next primarily about [Medical Home](#). She explained that the Medical Home is not so much a place as it is a patient and family centered concept that brings together both family and the healthcare professionals to improve outcomes for individuals with special health care needs. She also gave tips on how to get the most out of appointments with doctors and how to find a new primary care doctor or specialist if the one you have isn't working out. Family Voices has a [chapter](#) in almost every state in the U.S. Visit www.familyvoices.org for more information.

After lunch at the college cafeteria, families were back in the Underground to learn about accessibility in Home Design from Carisa Rasmussen of [Accessible Homes LLC](#). Carisa educated parents on how to think about accessibility as not just ramps and widened doorways. She talked about lifts, bathroom fixtures, light switches and kitchen cabinetry that can be modified to make it easier for someone with disabilities to live in their home. She also stressed the importance of finding capable contractors that are well versed in making special needs modifications to your home to avoid costly fixes later on.

Later in the afternoon, families crowded into a classroom where it was standing room only to see a presentation from Dr. Scott Winiecki. Dr. Winiecki is not only a former pediatrician but also the father of Wendy, who has 1p36 Deletion Syndrome. So his particular insight was very valuable to the attendees and the presentation and discussion was lively and entertaining. This was due partly because Scott is fun

and energetic and partly because he inserted adorable pictures of Wendy throughout his PowerPoint presentation!



The rest of the day was devoted to spending time together for the group photo, Balloon Release and Family Dance. The Balloon Release was in celebration of all those with 1p36 Deletion Syndrome including those no longer with us. It was quite a sight to see all those blue and green balloons sailing up into the sky. Directly after the balloon release there was a lot of dancing, laughing and talking at the Family Dance in the Underground complete with our own DJ, disco lights, glow sticks and Hawaiian leis!

On Saturday, the day began with a conversation with Ken Shirtcliff, President of 1p36 DSA, and board Secretary, Carrie Daggett, about 1p36 Deletion Support & Awareness. During the open discussion time, there was a chance to pass around the microphone to all the families so that they could share a little about themselves and their loved one with 1p36 Deletion Syndrome.

We were very happy to have Dr. Robert Hopkin of Cincinnati Children's Hospital as our key note speaker for the 2011 1p36 DSA Conference. Dr. Hopkin gave some insight on how he himself became involved in pediatric genetics and about the clinical approach to diagnosing a child with complex medical conditions such as those that are commonly involved with 1p36 Deletion Syndrome. He also talked more specifically about 1p36 Deletion Syndrome, its characteristics, how common the syndrome is and how it is diagnosed in the clinical setting. We were also very fortunate that Dr.

Hopkin was willing to come back to the Underground later in the day to do a Question & Answer session with families.



Part of Saturday afternoon was a fun outdoor time for families to enjoy learning about Therapeutic Horseback Riding from Joan Duncanson and take a spin on some adaptive bikes provided by Heather Marx with [Bikes for Everybody](#). The pictures speak for themselves. It was a great time and good example of how people with disabilities can take part in activities that would normally seem impossible to do.

Lori Burgess, a speech and language pathologist trained in reflexive integration, spoke to families later in the afternoon about communication strategies based on primary reflexes using a neurosensorimotor reflex integration method. To learn more about this approach developed by Dr. Svetlana Masgutova, click [here](#). Lori also shared different approaches to developing the best relationship and keys to look for with your local speech and language pathologist in order to get the best for your child.



After two full days of activities and speakers, families were able to relax and visit with each other Saturday evening watching movies and playing games in the common areas of the dorm.

Sunday morning marked the end of a wonderful weekend. Families said goodbye, promised to see each other at future conferences and headed home. The 2011 1p36 DSA Conference turned out to be a great success accomplishing the goal of bringing 1p36 Deletion Families together to learn, share and connect. Thank you to everyone who came and thank you to all the people that helped make it happen!

(A few of the speaker's presentations will be available streaming via the web at a later date so stay tuned.)

Carrie Daggett
1p36 Deletion Support & Awareness Board of Trustees

Planning a Local 1p36 Meet-Up



Not all 1p36 Deletion Support & Awareness members live in a place where they're able to easily attend the annual conferences. However, everyone needs someone to talk to about the challenges that make us alike.

Members are encouraged to plan meet-ups and spend time with other 1p36 families.

While no funding is available for these small meet-ups, everyone is encouraged to use 1p36

DSA internet resources such as our Ning network and Facebook group to reach out to others in their area. Visit 1p36dsa.org for more details.

**1P36 DELETION
SUPPORT &
AWARENESS**

E-Mail:

info@1p36dsa.org

We're on the Web!

See us at:www.1p36dsa.orgVisit our social
network at:1p36dsa.ning.com

and on Facebook at:

www.facebook.com/1p36DSA

2011 1p36 DSA Conference Acknowledgements

The 1p36 Deletion Support and Awareness wants to give big virtual round of applause to the following people for making this year's conference a huge success. Without you, there would be no conference. Thank you!

Big thanks to head conference organizer, **Beth Hegney**, who went above and beyond to create a great conference experience. Thanks also to **Heather Antoine** for her work before and during the conference.

Some other very helpful folks included **Clint Hegney** for his technical expertise and hauling of lots of stuff in and out of buildings and up and down steep grassy hills! And **Beth Peloquin**, for traveling from Vermont to help with whatever she was asked and for taking lots video and photographs. Thank you!

All the speakers and demonstrators donated their time and energy to our conference this year and for that we are very grateful:

- **Carolyn Allshouse, Executive Director of Family Voices of Minnesota**

- **Lori Burgess, SLP**
- **Joan Duncanson, Therapeutic Horseback Riding**
- **Barbara Gill, Author of Changed by a Child**
- **Dr. Robert Hopkin, Director of Genetics Residency Programs at Cincinnati Children's Hospital**
- **Carisa Rasmussen, Accessible Homes, LLC**
- **Dr. Scott Winiacki**
- **DJ Dave Holm**
- **Heather Marx with Bikes for Everybody**

Many local volunteers gave up their weekend to help out with childcare and assisting with other conference details and we want to acknowledge their gracious contribution. Thank you so much.

And finally thank you to the wonderful people at Bethel University for helping make our conference a great experience!

2012 1p36 DSA Conference To Be Held in Gatlinburg, Tennessee

The 2012 conference 1p36 Deletion Support & Awareness Conference will be held July 26-29 in Gatlinburg Tennessee. Registration information and a full agenda will be coming in early 2012. But we've already selected a location.

The conference will be at the Glenstone Lodge, 504 Nature Trail Rd. phone # [1-800-362-9522](tel:1-800-362-9522). If you decide to call and reserve your room(s) already, be sure to say that you are with the 1p36 group. We have a special rate of \$84.00 per room per night.

The Glenstone has an indoor pool and an outside pool. So no matter what the weather we can swim. There is a kiddie pool and a hot tub. They have an in house restaurant with a great breakfast buffet. There are also other restaurants nearby.

There will be child care provided during the conference. We will have a room to gather with snacks and drinks

Thursday. We will have conference sign-in and have time to socialize. We might have the first presentation then too.

Friday and Saturday we will have meetings and Sat afternoon we will have a Tennessee style cook out at the Riverdeck Pavillion.

There is a river right behind with places for fishing. The Glenstone is about 3 blocks from downtown Gatlinburg so it is a bit of a hike to get to downtown but there is a Trolley stop right at the hotel for those that would like to ride.

I am just so excited to have y'all coming I wish it was sooner but it will be here and gone before we know it.

Vicie Motz
2012 Conference Planning Committee

Important Fundraising Guidelines

There has been a great interest in raising funds fund on behalf of 1p36 Deletion Support & Awareness. We each have an opportunity to contribute to the organization's financial success.

We hope you'll consider holding a fundraiser of your own soon. When you do please keep the following guidelines in mind:

Each fundraiser must be approved by the 1p36 DSA Board. Email them at info@1p36dsa.org with a description of what you'd like to do to raise funds. We have put together a 1p36 Deletion Support & Awareness fundraising guide that we can send anyone who needs it.

The 1p36 DSA name and logo should only be

used for approved fundraisers. If you're raising funds for an individual 1p36 patient's needs, please use their name on the fundraiser to prevent confusion.

Keep all receipts for expenses that need to be reimbursed. Each receipt will need to be submitted to the 1p36 DSA Treasurer in order to obtain reimbursement.
