



1p36 Deletion SUPPORT & AWARENESS

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President's Message

As winter approaches, I wanted to fill everyone in on what has been going on with the Board of directors of your nonprofit. At the end of the summer the 2 year terms of Nate Hanson and Phoenix Schaefer came to an end. The remaining members of the Board of Trustees would truly like to thank both of them for their hard work over the last two years with all of their help in the initial formation of 1p36 Deletion Support & Awareness. Nate is still committed to helping us with the writing and organization of the 1p36 Deletion support & Awareness newsletter.

As of the end of September we are very excited to introduce Tod Oliver and Jason Friedman to the Board of Trustees. Please read their profiles below:

Tod is an Industrial Organizational Psychologist at NASA's Jet Propulsion Laboratory in Pasadena, California. He coaches, trains, and develops executives and their teams to enable robotic exploration of the universe. Tod graduated from the California School of Professional Psychology with a Ph.D. in Clinical Psychology and a MBA from San Diego State University. He is nationally certified as a Senior Professional in Human Resources. He is also a NASA Mariner Award winner for outstanding work in his field.

Tod has been involved with 1p36 DSA for the last three years. After attending the conference in Minnesota in 2011, he was inspired to take a more active role in this vital and much needed community. Tod has extensive experience working with other non-profits including the Community Research Foundation, Miracle Babies, and the San Diego Domestic Violence Council.

"Having a child with 1p36 has been the biggest challenge my family has ever faced. If there is any way I can help other families face the obstacles we encountered – medical, social, or emotional - I will do it to the best of my abilities."

Tod and his wife Amanda live in San Diego California with their three children, Devon age 8, Colin age 5 (1p36 Deletion Syndrome) and Peyton (19 months).

Jason is the Director of Sales Engineering for GetWellNetwork and enables patients in hospital rooms to become active participants in their care via an Interactive Patient Care solution. Jason graduated from Indiana University.

Jason and his wife Julie attended the 2nd Annual 1p36 Conference in Boston in

2008 shortly after their daughter Lily was diagnosed when she was 10 months old. The conference and families made such an impact on their lives that the Friedmans volunteered to coordinate and host the 3rd Annual 1p36 Conference in Indianapolis, Indiana in 2009. Jason joined the 1p36 DSA Board in 2011.

The Friedmans have hosted multiple fundraisers and raised nearly \$10,000 in an effort to support the Annual Conference. They believe the conference has the ability to give something powerful to 1p36 families: Hope. The hope and support the conference provides 1p36 families is invaluable.

Jason and Julie live in Indianapolis, IN with their 4 children; Nathan (11), Ella (9), Ava (7) and Lily (4).

New Board members are suggested by members of the 1p36 committee and then vetted by the existing board of trustees. The board of trustees then elects the new board members. We are always looking for more people to become involved with the organization. If anyone would like to help out, please e-mail me directly at k.shirtcliff@1p36dsa.org. We need people to put on fund raisers, be members of future committees, host a conference or be considered for a future board member opening. We are here to serve you and the 1p36 Deletion Syndrome community.

Ken Shirtcliff
President, 1p36 Deletion Support & Awareness

2012 1p36 DSA Calendar Released



Christina Ferguson, a 1p36 mom, has created a beautiful 2012 calendar featuring the faces of 1p36 Deletion Syndrome patients from around the world.

The calendar is spiral bound, 8 1/2" x 11" when closed and 11"x17" when open. Every month features 6 photos of beautiful individuals with 1p36 Deletion Syndrome.

Each calendar is \$20 with all proceeds going to 1p36 Deletion Support & Awareness.

To place your order on line, please visit <http://onep36.squarespace.com/1p36-dsa-blog/2011/10/27/buy-a-2012-1p36-dsa-calendar-to-show-your-support.html>.

If you would prefer to order by check, please make the check out to 1p36 Deletion Support & Awareness. (No Cash Please) Mail to 1p36 Deletion Support & Awareness, Attn: Karen Bess, 48 Cornfield Lane, Warwick NY 10990 Include a note regarding how many calendars you are ordering and the address where you would like them sent. Please see the note below for international shipping info.

Calendars will printed and shipped in one batch to avoid unneeded costs.

Deadline for Orders: November 21st, 2011
Estimated Ship Date: December 5th, 2011

*Shipping outside the US? Yes we can! However, there will be an additional charge for shipping so please email c.daggett@1p36dsa.org before placing your order. Include your address and how many calendars you are ordering. The additional shipping cost will be calculated and emailed to you so that you can include that amount in your payment.

Vote for 1p36 DSA in the Chase Community Giving Contest

1p36 Deletion Support & Awareness needs your help! We are on a quest to win an award ranging from \$25,000 to \$250,000 through Chase Community Giving. Here are the basics: the Top 100 eligible organizations with the most votes will share \$3.0256 million—the top charity will win \$250,000, and the remaining 99 charities can earn anywhere from \$25,000 to \$100,000.

Now that we've got your attention, it's time to start generating buzz for 1p36 Deletion Support & Awareness—and time to show the world why our organization is worthy.. And to gather the most votes, we need to get the message out to our friends, family, and supporters, but also the broader community of people in your city, state and region.

Voting runs from Tuesday, November 8th through Tuesday, November 22nd. Unlike the Pepsi Refresh Everything fundraiser we tried last year, you can only vote once. So it is very important that we really get the word out to everyone you know. All voting is done on Facebook through the Chase Community giving App. You will need to accept the terms of the app and then get voting. You can find our voting page by going to <http://bit.ly/lAmtmb> or you can search for 1p36 from the Chase Giving Page. If you

have any problems please email me at k.shirtcliff@1p36dsa.org.

One effective and easy way to get the message out is through the media. A simple mention in the pages of your local newspaper or on the airwaves of your local radio or TV stations, or community blog can potentially generate real results and get us closer to winning. If you need help drafting a press release please contact us, we have sample drafts available. You can spread the word to people you know through Facebook, Twitter, and if you write a blog. If you have children who are old enough to have a Facebook account, get them involved. Have them spread the word with their Facebook friends. Print out a flyer they can take to school to get their classmates to vote. Involve your kid's special ed. teachers and therapists. There are hundreds of ways to get others involved, these are just a few. During this campaign we will post updates to the 1p36 DSA Facebook page as well as the Facebook support group. If you think of a great way to get more people to vote, please let us know.

2012 Conference Plans Are Continuing

1P36 DELETION SUPPORT & AWARENESS

E-Mail:

info@1p36dsa.org

We're on the Web!

See us at:

www.1p36dsa.org

Visit our social
network at:

1p36dsa.ning.com

and on Facebook at:

www.facebook.com/1p36DSA

The 2012 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. 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 also 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

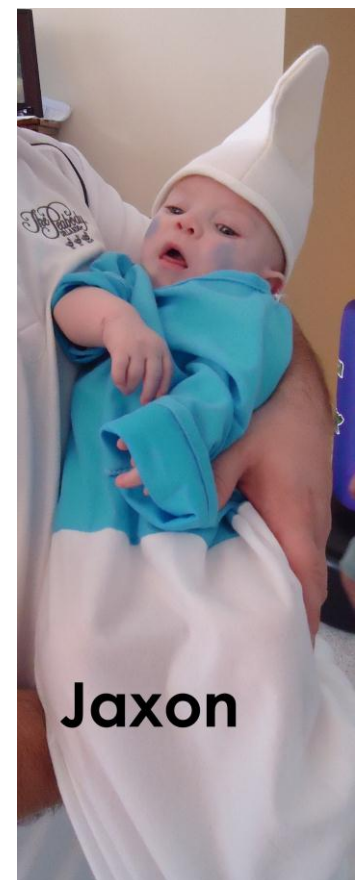
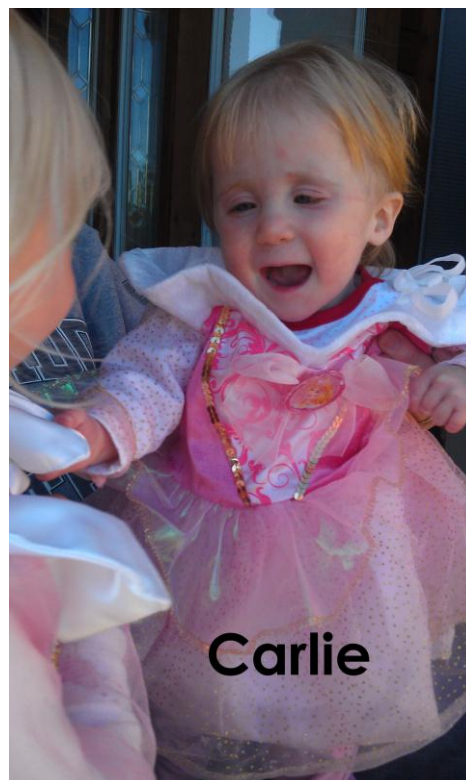
New 1p36 DSA Website Launches

After several months of hard work, 1p36 Deletion Support & Awareness is very excited to launch our new redesigned website. The board of trustees felt that a new website design was needed to better tie in with our new logo that was debuted in July at the Annual Conference. The new website is clean and modern in appearance, easy to navigate and has much more information available than the current site. The new website platform also allows us to continually update information and keep the 1p36 Deletion community abreast about the newest information about the syndrome, conferences, fundraising and much more. The new website is the one place to go for the 1p36 Deletion Support & Awareness Blog, Apparel Shop and Annual Conference information. Our hope is that both families with a new diagnosis as well as those who have been part of the community for

years will be able to get all the information they may need from the new site.

There is also a registration page that will allow you to access members-only information. Right now if you register on the website you will be able to access the 2011 Annual conference videos. Many of you have been asking and they are finally available. All you need to do is register and click on the "for families" tab, then conferences and follow the links to the 2011 conference. The sound quality is not as good as we would have liked but if you turn your speakers up loud you will be able to listen to many of the Speakers who presented at the 2011 1p36 Deletion Support & Awareness Annual conference. The web address is still www.1p36dsa.org so go visit and explore today.

1p36 Halloween Picture Parade





Hunter



Carter



Jason



Wendy



Joseph



Uisneach



Leila



Sydney



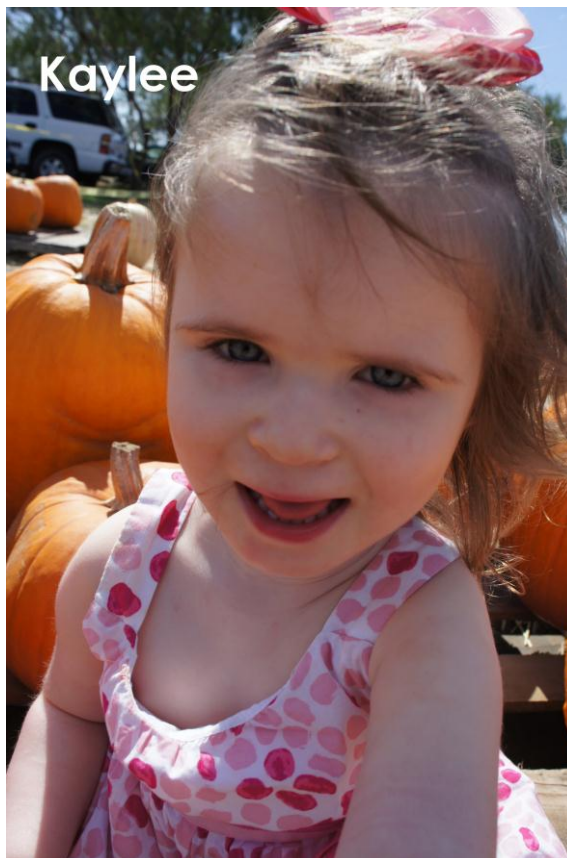
Mauricio



Whitney



Kate



Kaylee



Lauren



Mollie