



The Blue Ribbon Tribune

Official Newsletter of 1p36 Deletion Support & Awareness
Winter 2010

Inside this issue are more details about the progress of 1p36 Deletion Support & Awareness as an organization and plans for this summer's conference. Here's a full list of everything inside this issue:

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1p36 Deletion Support & Awareness Receives 501c3 Status

1p36 Deletion Support & Awareness has now received federal 501c3 tax status. Work began on obtaining United States 501c3 status shortly after 1p36 Deletion Support & Awareness was incorporated. The process involved retaining a legal team, creating plans for the future of the organization and then submitting paperwork and application fees to the Internal Revenue Service. Getting this official status in the US is very important because it will pave the way for larger corporate donors. These donors can now receive a credit on their taxes for donations made to the organization. Most large firms will not even consider contributing to an organization until this status is achieved.

In December, after waiting several months for the paperwork to be processed, 1p36 DSA was finally recognized as a non-profit organization! This is exciting news that will lead to greater growth and recognition for the group. Which will in turn help us fulfill our mission to be there for individuals and families affected by 1p36 abnormalities.

As members raise funds for 1p36 DSA, they should make contributors aware that they can claim a tax credit for the donations they make. More information, including our tax ID number and guidelines for raising funds, is available by contacting the 1p36 DSA Executive Committee at 1p36dsa@gmail.com.

Make Reservations Now for the 2010 1p36 DSA Conference in Salt Lake City



Arrangements with the site for our 2010 conference are now complete. The Downtown Marriott at 75 South West Temple in Salt Lake City is excited to host our group Thursday evening, July 29th through Sunday morning, August 1st. The hotel boasts a great location in the center of downtown Salt Lake with dining and entertainment nearby. There is a large indoor/outdoor pool and they'll be holding two conference rooms for use by our group.

For conference attendees, rooms at the hotel will cost \$99 a night plus tax or for \$109 a night plus tax the Marriott will include two adult breakfasts in the hotel restaurant along with the room. Ordinarily, adult breakfasts in the restaurant are \$15 each so this is a nice discount.

These room prices are also available for check in as early as Monday, July 26th and as late as checkout Monday, August

2nd for those who would like to come early or stay a bit late to enjoy the city.

Not every room includes a microwave or refrigerator but those who would like them can request them for no additional charge when reservations are made.

Parking at the hotel for those who drive to the conference or rent a car will be \$12 a day with unlimited reentry to the covered parking structure.

A shuttle to and from the airport will be available from a third party. The conference committee is negotiating prices for this and will have an update soon.



To make hotel reservations please call 1-800-455-8254. Remember to tell them you're coming for the conference so you get the special group rate. The 2010 conference committee has reserved 35 rooms at the \$99 or \$109 rate and they will only be available until July 8th so please make your reservations now.

Preliminary 2010 Conference Agenda Announced

Now in it's fourth year, the annual 1p36 Deletion Support & Awareness Conference continues to grow. This year the conference will be bigger and more exciting than ever. The 2010 conference committee has begun to block out a preliminary agenda so attendees will know what to expect during each day of the conference:

Thursday, July 29th

Travel day
Evening: Conference Check in
Optional Meet and Greet in the lobby area

Friday, July 30th

Morning: Conference Check in
Speakers & Panels

Afternoon: Activity
Evening: Mom's night & Free time

Saturday, July 31st

Morning: Dad's Breakfast, Speakers & Panels
Afternoon: Activity
Evening: Free time

Sunday, August 1st

Travel day

Time for speakers, workshops and question and answer panels will be spread across Friday and Saturday mornings. Speakers will be selected from among physicians, researchers,

therapists and others who have important information to share with regard to 1p36 Deletion patients and their families.

Afternoon activities such as a trip to a local children's museum or a visit to local historic sites are tentatively planned. Time in the evenings is left open for whatever attendees would like.

One evening a Mom's night is planned for all the mothers to get away (without kids if possible) and have a chance to be together.

One morning the Dad's Breakfast will allow the fathers in the group a similar opportunity.

And of course attendees don't have to travel Thursday and Sunday. There are plenty of places to visit in or near Salt Lake City. To take a peek at things your family might enjoy during your stay please see slctravel.com.

To keep up on continuing plans for the conference and to share your excitement with other attendees, visit 1p36dsa.org, 1p36conference.blogspot.com or visit the 1p36 DSA 2010 Conference Facebook event page. If you have any questions you'd like to have specifically answered as you make plans to attend, please email Melanie Hanson at melanie.hanson@gmail.com. See you this summer!

DVDs of 2009 Conference Now Available

The entire 2009 1p36 Deletion Support & Awareness Conference is on 3 DVDs:

Disc 1 - Therapist Panel; Gordon Holmes Jr. - Special Needs Estate Planning

Disc 2 - Dr. Lisa Shaffer - Signature Genomics Laboratories; Robin Jones - Sign Language Workshop,

Disc 3 - Dr. Kevin Bax - GI Presentation; Dr. Anthony Perszyk - Pediatric Development Geneticist; Nate Hanson - 1p36 DSA Introduction; Jason Friedman -Closing Remarks

The cost of the the DVD set is \$5.00 within the U.S. and Canada to cover the expense of supplies and shipping .

Outside of the U.S.and Canada please email 1p36DSA@gmail.com with your address and we will calculate shipping.

To order a DVD, you can send a check / money order or use Paypal. Send checks or money orders to:

1p36 Deletion Support and Awareness
Attn: Karen Bess
48 Cornfield Lane
Warwick NY 10990

Include the following information with check:

2009 Annual 1p36 DSA DVDs
Name & Address to Send DVDs

To purchase via Paypal:

Go to our web site, www.1p36dsa.org, and click donate.

Include DVD in the notes section on the donation page. DVDs will be sent to the billing address entered.

Once payment is received it will take approximately 2-4 weeks before you receive the DVDs.

Please email 1p36DSA@gmail.com with any questions.

Member Messages

This issue in our Member Messages section we have a special report from Kasja Farnsworth, Brady's mom, about assistive communication devices. Thanks, Kasja for all your work to put this article together and share it with the group!

Augmentative and Alternative Communication

By Kajsja Farnsworth

Finding a means to help our nonverbal son Brady to communicate his needs

and desires continues to be a learning process for us as parents. Brady has

good receptive language but his expressive language, even babbling, has been very minimal so far. While we haven't given up on him talking one day, it became clear early on this boy needed a way to speak his mind.



In the beginning we relied on following our son's gaze to determine what he wanted. Thankfully, the growing popularity of sign language (particularly the Signing Time video series) introduced us to a form of Augmentative and Alternative Communication (AAC) which greatly reduced Brady's frustrations. However, his progress with signing seemed to stall after about a year as he dropped some signs and would often invent new signs we couldn't figure out. It was also difficult for family members or babysitters to interact with Brady if they didn't know sign language. Around this time Brady started pre-school and we were introduced to the Picture Exchange Communication System (PECS).

Brady picked up PECS very quickly, which I believe was a direct result of the fact that his classroom is specifically geared towards nonverbal children. A speech or occupational therapist is almost always present and his teacher is very experienced with PECS. They sent us home with

laminated pictures with Velcro on the back and we created a book with pages color-coded for various needs and activities. At this time we also took note of how much Brady loved electronic toys. Once we learned that many Augmentative Communication Devices use the same symbols as PECS we decided to look into this option.

With the help of our home speech therapist we set up an evaluation meeting with the state to test a variety of devices ranging in complexity and function. Based on the evaluators' recommendations Brady was approved for the Prentke Romich Vantage Lite, which we affectionately refer to as his "talker." This was a triumphant day for us as we often hear of school districts which do not have the supports in place for a more complex device or may refuse to fund such a device.

Our initial elation after receiving the device was soon replaced with a mix of emotions. Hearing "I want Mom" for the first time brought tears to my eyes. But some days the robotic computer voice makes me sad. Most days Brady enjoys pushing random buttons and stringing together incoherent phrases. We have spent late nights programming the device and uploading pictures to find out later we had to start over because we hadn't followed traditional language acquisition patterns. We are still very new to this device and are hopeful about the future. Brady's teacher reports a lot of successes during the school day (saying "hi" to classmates on his own, etc.). We are learning that a tremendous amount of time an effort must be put into this device in order

for it to be effective. The pros have definitely outweighed the cons and the following factors have been crucial to our progress thus far with the device:

- Brady's school teacher, therapists and the district have been willing and able to learn and support the device. The district has a dedicated AAC facilitator who knows this specific device in and out and has set up training meetings for all (including parents) involved in Brady's education. The district also facilitates a monthly night out for families with "talkers" so their children can learn from other children using similar devices.
- The state provided 12 hours of training for us on the device. However, finding a speech therapist who knows this particular device has been challenging.
- The device manufacturer provides technical support via phone for those moments when one of us pushes a combination of mystery buttons rendering the device inoperable.
- Family members and friends can understand the device and enjoy watching Brady navigate through different screens.
- Brady's continues to learn and utilize sign language and PECS. We were happy to learn this is appropriate and that Brady did not need to drop his other forms of communication for the device to be effective.

- There is a vast amount of information out there on the web as similar devices have been used for decades. There exists an extremely wide range of devices from one- or two-button devices (Brady currently utilizes a 45-button device) to complex computers which can be controlled by eye movements.



Information on Augmentative and Alternative Communication can be found at the following:

<http://www.ussaac.org/>

Some of the more common devices (including demonstrations) can be found at the following:

<http://www.prentrom.com/>

<http://www.dynavotech.com/>