



The Blue Ribbon Tribune

Official Newsletter of 1p36 Deletion Support & Awareness
 Summer 2010

Inside this issue: 1p36 Deletion Families are getting together. Fundraisers for 1p36 DSA are huge successes. 1p36 Deletion Support & Awareness gets high ranks with a popular non-profit directory and more! Here's a full list of everything inside:

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Vote for 1p36 Deletion Support & Awareness in the August Pepsi Refresh Contest



Each month Pepsi holds a contest for grants to charitable organizations around the US. Winners are determined through a popular vote on <http://www.refresheverything.com>. Voting takes place for the period of a month and after that the winner is announced.

In August, 1p36 Deletion Support & Awareness is in the running for a \$50,000 grant from Pepsi, but we need your help to win. The public can vote once each day during the month and at the end of the month the winner will be announced.

We need your help in making sure the word gets out to everyone to come and vote. And don't forget to visit www.refresheverything.com, create an account and vote for 1p36 DSA each and every day in August. We'll share the progress as the month goes on.

1p36 Families Are Getting Together

Families with 1p36 Deletion patients are getting together all over the world. Here are highlights from a few of the recent play dates and gatherings. If you've had a get together, send us

news about it along with some photos so we can feature you in The Blue Ribbon Tribune.

N.hanson@1p36dsa.org

Jason & Aiden – NY



Jason (30 months old) and Aiden (33 months old) had a play date in Warwick, NY on June 27th. The boys spent the afternoon playing with toys



and swimming in the pool. Both boys loved the water and look forward to having another play date sometime soon!

Ameeliah, Lexi & Scarlett – United Kingdom

On the morning of the 18th of June, 2 special friends, Ameeliah and Lexi, met for the 1st time. We went for breakfast and then had a day spent with the adults doing most of the talking. We played and swapped presents. Scarlett who also has a 1p36 Deletion and her family came too and joined the fun. We also went out 4

dinner which was very nice and then to a Funday (a celebration day 4 caregivers of children with special needs) with lots of fun things to do including face painting, outdoor activities, special bikes, food and fruit cocktails. It was all very fun and exciting and we all can't wait to meet again very soon. xxx



Tabitha, Riley & Kayleigh - Tennessee

Tabitha (Tennessee), along with Riley (North Carolina), and Kayleigh (Tennessee) got together for an evening of fun in April! What a

wonderful evening it was playing with toys, and bonding with the other families!"



1p36 Deletion Support & Awareness Fund Raisers

Group members are also working very hard to help raise funds for 1p36DSA to help the organization better fulfill its mission. Thanks to everyone who

has put together a fund raiser so far this year. Here are a few of the highlights:

St. Maria Goretti Catholic School, Westfield, IN

A letter from Mrs. Rebecca Hammel, Principal of St. Maria Goretti Catholic School:

Each month St. Maria Goretti Catholic School sponsors a "Charity Day" to instill the values of compassion and selflessness in our Kindergarten through 8th grade students. Grade levels take turns determining which charity or organization we sponsor

and what our students may wear in place of their school uniform. Students must then pay \$1.00 to participate, all of which we offer to the selected charitable organization.

For the month of February 2010 our 1st Graders chose your support and awareness group as the recipient of our donation. I am happy to present a check in the amount of \$324.25 to

help you in your endeavors. We are all grateful for the compassion and love with which you serve each day. Sincerely, Mrs. Rebecca Hammel

*A special thank you from 1p36 DSA to the Friedman children for deciding they wanted their school to donate to our organization in support of their sister Lily.

2010 1p36 Scrapbooking Extravaganza



The Friedman Family hosted the 2nd annual 1p36 Scrapbooking

Extravaganza Feb 20, 2010 at the Carmel Lions Club in Carmel, Indiana. The cost was \$45.00 per person (\$35.00 if you registered by Feb 6th). \$1,613.40 from sales and entrance fees was collected for 1p36 DSA.

A special thanks to the event sponsors: Carmel Lions Club, Starbucks, Jill Sutton – Creative Memories Consultant, Jeanne Spaletto – Creative Memories Consultant and McAlister’s Deli.

Shawn’s Big Fat 50th supporting 1p36 Deletion Support & Awareness



Shawn celebrated his 50th birthday with a big birthday bash at Shawn O’Donnell’s Restaurant in Everett, WA. Family and friends showed up to celebrate the event as-well-as support Shawn’s daughter Kate by making a donation to 1p36 Deletion Support & Awareness. \$1,555.00 in donations was collected for 1p36 DSA.

Raise money for **1p36 DSA** when you search or shop online!



Raise a penny (or more!) for 1p36

DSA every time you search the web.

iSearchiGive.com is a search engine powered by iGive.com, the internet’s first online shopping mall where a portion of each purchase is donated to your favorite cause. Over 750 of the web’s best stores participate in this

free program, and up to 26% of each purchase benefits our cause! **Totally Free, No Hidden Fees and No Limits!** Since Jan 2010, \$120.00 has been raised for 1p36 DSA by 54

supports. Create a new account www.iGive.com/1p36DSA and make your 1st purchase within 45 days of joining and 1p36 DSA gets an extra \$5 bonus donation.

1p36 Deletion Support & Awareness Cause Page



Many people find out about our organization through the 1p36 DSA cause page on Facebook. Just over \$500.00 was donated to our organization through the cause page from Jan 2010 – June 2010. Are you on Facebook and not a member of our cause page? Please join @

causes.com/support1p36DSA. Once you are a member of our cause, you can invite your friends and family to join too. Currently, we have 1,338 members. Our goal is reach 2,500 members before the end of the summer, 1,162 more members!

1p36 Deletion Support & Awareness T-shirt Fundraiser



T-shirts with the 1p36 DSA logo were sold from May 25th – June 30th. The

cost per t-shirt was \$10.00. A total of 192 t-shirts were sold! Each t-shirt was a \$3 profit, to raise a total profit of \$576.00!!!

Some t-shirts will be available for sale at the conference, but only limited sizes and colors. Thank you to Robin Jones, mom to Abby, for setting up and organizing the fundraiser. A special THANK YOU to Larry, owner of [Kewl Threadz](http://KewlThreadz) of Madison, Indiana for giving 1p36 DSA a discount on each t-shirts and 35 t-shirts free!

Company Charitable Matching

Charitable matching is when a company matches the donation amount made by an associate to a charity. Currently, 2 companies, BD and Roche, have 1p36 DSA listed as a charity that can receive charitable matching. Does the company you

work for have charitable matching? If so, please contact Karen Bess, k.bess@1p36dsa.org to get the process started so your company can match contributions made to 1p36 DSA.

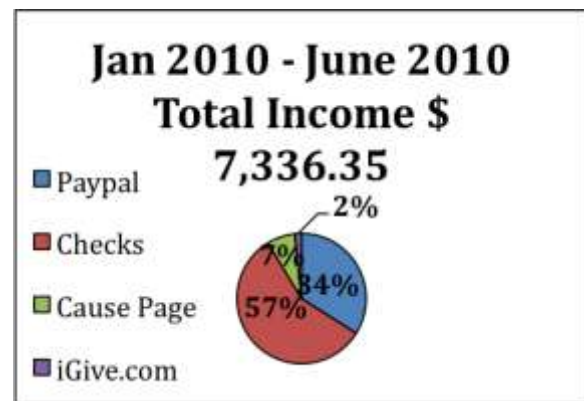
Please help raise funds for 1p36 Deletion Support & Awareness!!

It takes a lot of funding to host the annual conference, maintain the 1p36dsa.org website and run other programs sponsored by the organization. We rely on the excellent fundraising efforts of 1p36 Deletion Support & Awareness members, family and friends to support future events. To help we've put together an

official guide to putting together a successful fundraiser. It provides tips to make your fundraising efforts as effective as possible and gives guidance on how to make sure donors receive the proper tax credit for their donation. To download the guide, visit 1p36dsa.org/donate.html and click on Fundraising Idea.

Quarterly Financial Report

1p36 DSA's total income from Jan - June 2010 was \$ 7,336.35. The income came from PayPal, checks and our cause page. The total expenses for the same time period were \$1,011.38. The expenses were for the website, conference and online transactional fees. The pie charts below show the percentages of where the income came from and the expenses went to.



1p36 DSA Ranked Top-Rated by Great Nonprofits



1p36 DSA is a top-rated Health Nonprofit on GreatNonprofits. During June, over 50,000 people visited the GreatNonprofits site to read and write reviews about 278 nonprofits improving the health of our communities. During the coming weeks, 1p36 DSA will be promoted as

a top-rated organization on GreatNonprofits, Guidestar, and beyond.

GreatNonprofits is the leading developer of tools that allow people to find, review and share information about great nonprofits. If a person has

direct experience with a charitable organization, GreatNonprofits makes it easier for him or her to share that knowledge so that other people can discover that group as well.

To read or post a review of 1p36 DSA, [CLICK HERE](#).