



# The Blue Ribbon Tribune

Official Newsletter of 1p36 Deletion Support & Awareness  
Spring 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 Featured in the Genetic Alliance Weekly Bulletin



The Genetic Alliance sends out a weekly email bulletin to its members with all kinds of useful information. One section of the weekly bulletin is Meet Your Neighbor. It features a related organization or Genetic Alliance

member. The week of May 4<sup>th</sup>, 2010, 1p36 Deletion Support & Awareness will be featured in Meet Your Neighbor. This will provide the wider community and help promote awareness for families affected by 1p36 Deletions. To sign up for the Genetic Alliance Weekly Bulletin or share it with friends, please visit [geneticalliance.org](http://geneticalliance.org).

## The 2010 1p36 DSA Conference Is Almost Here



The fourth annual 1p36 Deletion Support and Awareness conference will be held in Salt Lake City, Utah on July 29<sup>th</sup> through August 1<sup>st</sup> 2010. Conference sessions will be held at the Downtown Marriott hotel at 75 South West Temple. Rooms are available to conference attendees at a special discount rate of \$99 a night or \$109 with two included adult breakfasts. To make hotel reservations please call 1-800-455-8254 before July 8<sup>th</sup>. Mention 1p36 DSA to get the discounted rate.

The final conference agenda includes speakers such as Lisa Shaffer of

### Participate in 1p36 DSA Fund Raising

It takes funding to host the annual conferences, the 1p36dsa.org website and run the other programs sponsored by the organization. We rely on the excellent fund raising efforts of 1p36 Deletion Support & Awareness members and their friends.

We need you to help keep support rolling in for future events. To help we've recently completed an official

Signature Genomics, a panel of speech, occupational and physical therapists, and a special session for siblings.

Activities are planned for attendee families in the afternoons on Friday and Saturday. There will be outings to the Discovery Gateway, the local children's museum, as well as other popular spots in Salt Lake. Another informally planned outing for those who are in town on Thursday morning is being planned by makkiesmom and Robin Jones on the Yahoo Goup. They're working out details for a trip to Hogle Zoo.

There will also be a "Moms Time" and a "Dads Time" to get together and just talk over things that are on their minds

It's going to be a great conference and there are still rooms available. Make your reservations soon. See [1p36conference.blogspot.com](http://1p36conference.blogspot.com) for more details.

guide to putting together a successful fundraiser. It gives tips to make your fund raising efforts as effective as possible and guidance on how to make sure all your donors receive the tax credit they deserve for their donation.

To download the guide, visit [1p36dsa.org](http://1p36dsa.org). And watch for more fundraising ideas and details in the Summer edition of The Blue Ribbon Tribune.



**1p36 Deletion Support & Awareness Donation Form**

Please send this form along with your check donation (do not send cash) to:

1p36 Deletion Support & Awareness

Attn: Karen Bess

48 Cornfield Lane

Warwick, NY 10990

**Contact Information:**

First Name: \_\_\_\_\_ Last Name: \_\_\_\_\_

Email: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Donation in Honor / Memory of: \_\_\_\_\_

1p36 Deletion Support & Awareness is a non-profit 501(c)3 company. Tax Donation receipts will be sent to the email address provided above 2-4 weeks after receipt. Credit card donations can be made via the [1p36dsa.org](http://1p36dsa.org) website.

## **Financial Report January - March 2010**

Opening Balance (Jan 1st 2010): \$12,267.99

Total Income: \$1638.30

Donations:

- Checks \$873.54

- PayPal \$525.60

- Network for Good \$237.16

Total Donations \$1636.30

Interest: \$2.00

Total Expenses: \$89.75

Closing Balance (March 31, 2010): 13,816.54

### **Company Charitable Matching Programs**

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. How can you help? Does

the company you work for have charitable matching? If so, please contact Karen Bess, [karen\\_bess@yahoo.com](mailto:karen_bess@yahoo.com) to get the process started so your company can make contributions to 1p36 DSA.

### **Member Messages**

This issue's Member Message comes from Phoenix Schaefer. She shares some great tips about safety in the great outdoors this summer.

And don't forget, as a reader of this newsletter you are eligible to submit a reader story about any topic you like. Maybe you've discovered an exciting

therapy that is doing wonders for your child. Or perhaps you have a great idea for a fundraiser. Anything that gets you excited will make a great submission. Please contact Nate Hanson at [nate.hanson@gmail.com](mailto:nate.hanson@gmail.com) to arrange for your message to be printed here next issue.

## Bugs & Boo-boos

Out here in the sticks, the warm weather brings out the best of times for most of us, but it also brings many dangers. It's easy to overlook the common dangers, and focus on the bigger ones, like the pond in my back yard. That pond has never really been a problem because proper precautions have always been taken to prevent harm from occurring, but I'm not so good with the common dangers.

While playing with my children out and about on the family grounds I had a reality check from a series of events; Thankfully my children were safe and secure in the fenced in playground (which separates them from that beautiful pond down over the hill). I pitched a fit about having that fence in place so I could work in my garden without feeling guilty for looking at the dirt instead of the children and where they were. Open spaces are good for new discovery, but let's face it there is always a limit for safety purposes. The pond isn't even a part of the series of events that now has me rethinking about safety improvements and scratching my head.

I was working in my garden and running back and forth between there and my porch and I almost broke my ankle cause of a sink hole, where a tree had previously been. We've filled it in every year with dirt from the garden, but every year it takes someone tripping in it first. (It's usually me) Well, check, hole filled in.

Walking back to my garden I notice something shiny and bent over to pick it up. (Ever heard "Look but don't touch", yea should have applied it) A strip of aluminum smashed down into the ground and I cut my finger when I tried to pick it up. Well after cleaning that up along with several other things that had blown into my yard I was ready to go in. I was herding the kids into the house, when not paying attention cause I was too busy watching Tru paying attention to walking up the steps, I stubbed my toe (in flip flops no less) on a stone that had shifted due to weather. And has anyone noticed how bad the bugs are this year? It's strange how I can remember to put sunscreen and bug spray on the kids, but it's just too much work for me to do it for myself.

What I'm getting at though is that with the weather being warmer, everyone wants to be outside and simple safety tips can keep everyone, or at least me, from getting hurt and eaten up by pests.

- ✚ Check yard for holes and other obstructions that could cause harm. (That's mainly for me, but here are some more really good tips for everyone.)

### ✚ **BUG SAFETY**

- ✚ Don't use scented soaps, perfumes or hair sprays on your child.
- ✚ Avoid areas where insects nest or congregate, such as stagnant pools of water, uncovered foods

and gardens where flowers are in bloom.

- ✚ Avoid dressing your child in clothing with bright colors or flowery prints.
- ✚ To remove a visible stinger from skin, gently scrape it off horizontally with a credit card or your fingernail.
- ✚ Combination sunscreen/insect repellent products should be avoided because sunscreen needs to be reapplied every two hours, but the insect repellent should not be reapplied.
- ✚ Insect repellents containing DEET are most effective against ticks, which can transmit Lyme Disease, and mosquitoes, which can transmit West Nile Virus and other viruses.
- ✚ The current CDC and AAP recommendation for children over 2 months of age is to use 30 percent DEET. DEET should not be used on children under 2 months of age.
- ✚ The concentration of DEET in products may range from less than 10 percent to over 30 percent. Ten percent DEET only protects for about 30 minutes – inadequate for most outings.
- ✚ For more information on DEET: <http://www.aapnews.org/cgi/content/full/e200399v1>
- ✚ **PLAYGROUND SAFETY**
- ✚ The playground should have safety-tested mats or loose-fill materials (shredded rubber, sand, wood chips, or bark) maintained to a depth of at least 9 inches. The protective surface should be installed at least 6 feet (more for

swings and slides) in all directions from the equipment.

- ✚ Equipment should be carefully maintained. Open “s” hooks or protruding bolt ends can be hazardous.
- ✚ Swing seats should be made of soft materials such as rubber, plastic or canvas.
- ✚ Make sure children cannot reach any moving parts that might pinch or trap any body part.
- ✚ Never attach—or allow children to attach—ropes, jump ropes, leashes, or similar items to play equipment; children can strangle on these.
- ✚ Make sure metal slides are cool to prevent children's legs from getting burned.
- ✚ **GRILLING SAFETY**
- ✚ If possible block off the grill so that children do not have access to it while it's hot.
- ✚ Check grill hoses for cracking, brittleness, holes, and leaks. Make sure there are no sharp bends in the hose or tubing. (FOR LP GRILLS)
- ✚ Move gas hoses as far away as possible from hot surfaces and dripping hot grease. If you can't move the hoses, install a heat shield to protect them. (FOR LP GRILLS)
- ✚ Replace scratched or nicked connectors, which can eventually leak gas. (FOR LP GRILLS)
- ✚ Check for gas leaks, following the manufacturer's instructions, if you smell gas or when you reconnect the grill to the LP gas container. If you detect a leak, immediately turn

off the gas and don't attempt to light the grill until the leak is fixed. (FOR LP GRILLS)

- ✚ Keep lighted cigarettes, matches, or open flames away from a leaking grill. (FOR LP GRILLS)
- ✚ Never use a grill indoors. Use the grill at least 10 feet away from your house or any building. Do not use the grill in a garage, breezeway, carport, porch, or under a surface that can catch fire.
- ✚ Do not attempt to repair the tank valve or the appliance yourself. See an LP gas dealer or a qualified appliance repair person.

AND MOST IMPORTANTLY HAVE FUN  
AND MAKE EVERY DAY A BEAUTIFUL  
DAY.