



The Blue Ribbon Tribune

Official Newsletter of 1p36 Deletion Support & Awareness
Winter 2011

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A Message from Ken Shirtcliff, 1p36 Deletion Support & Awareness President



On behalf of the board of 1p36 Deletion Support & Awareness, I would like to wish everyone a happy new year. We would also like to thank everyone who has held fundraisers in support of 1p36 Deletion Support and Awareness and those of you who have volunteered your time to help with last summer’s conference in Salt Lake City. We have so many wonderful parents, caregivers and others that are involved with an individual with 1p36 Deletion Syndrome and all of you are what make 1p36 DSA what we are.

2010 was our first full year as an organization and it has been a wonderful first year. We have a very active online community that has transitioned to primarily using Facebook for communication but also use the original Yahoo Health message board. In March we launched our official website, www.1p36DSA.org, and since that time it has averaged almost 2,000 unique visitors every month. Our hope is to be able to have our website be the first site that people visit to get more information about 1p36 Deletion Syndrome. In August, September and October we were entered into the Pepsi Refresh Project to try and get a grant for

\$50,000. Although we did not win, we raised a lot of awareness for our cause and made partnerships with other similar organizations. We thank all of you who logged in everyday and voted and also put up with the constant Facebook reminders from all of us. I am really proud of how well we did for such a small organization. We look forward to an even better 2011. We will be having our 5th annual 1P36 DSA conference this summer.

We hope to expand and make more improvements to our website and we are learning everyday how to be a more effective and responsive organization that serves the 1p36 family the best we can.

Ken Shirtcliff
President, 1p36 Deletion Support & Awareness

The 5th Annual 1p36 Deletion Support & Awareness Conference will be in Minneapolis-St. Paul, Minnesota



On behalf of 1p36 Deletion Support and Awareness, I would like to invite you to the 2011 1p36 DSA Family Conference and Retreat held in Minneapolis-St. Paul, July 14th-17th. For the past four years, we've welcomed new and old families with members who have 1p36 Chromosome Deletion in learning new information, sharing our stories and spending time together.

This year, we invite you to get away with us as we meet on the beautiful campus of Bethel University in Saint Paul, Minnesota on the shores of Lake Valentine. Located just 20 minutes from both downtown St. Paul and Minneapolis, 25 minutes from MSP International Airport and 30 minutes

from the Mall of America. We'll enjoy the comforts of the city and the quiet retreat of Bethel's 245-acre campus. You might notice things look a little different this year. First, we're pleased to offer an "all-inclusive" style retreat. Registration fees will include lodging, meals, access to speakers, conference materials and activities. You'll find a blend of dynamic speakers with topics ranging from advocacy to education, ideas for adaptations and encouragement to face the daily challenges along with times to relax and enjoy being with our "1p36 Family".

Look for more information in the month of February such as online registration, conference activities and

local information on the DSA's website at: www.1p36dsa.org. Registration will begin March 1st. Until then, I invite you to explore Minnesota and the Metro area at: www.exploreminnesota.com. We

look forward to “retreating” with you in the Land of 10,000 Lakes!

Beth Hegney
2011 1p36 DSA Conference
Committee

Use the Internet to Raise Funds



eBay sellers can now give a percentage of their proceeds to 1p36 DSA through MissionFish each and every time they list an item for sale. Participating eBay sellers are rewarded for their generosity with special eBay Giving Works features that help them get more bids and higher sale prices. 1p36 DSA receives recognition in the listing and benefits from the seller's success. A special thanks to John Campell for suggesting the idea and listing a percentage of the sales of his eBay items to benefit 1p36 DSA.



Searching and shopping online is a great way to donate to 1p36 DSA. Over \$450.00 has been raised to date by shopping through igive.com. A penny or more per search, a \$5 bonus for your first purchase and up to 26% of your purchases at over 730 stores like Amazon, Gap, Home Depot and many, many more. Plus you SAVE money with exclusive coupons and free shipping deals.

Millions Around World To Observe Rare Disease Day



1p36 Deletion Support & Awareness will be joining the National Organization for Rare Disorders (NORD) and others around the world in observing World Rare Disease Day on February 28, 2011. On this day,

millions of patients and their families will share their stories to focus a spotlight on rare diseases as an important global public health concern.

“There are nearly 30 million Americans—and millions more around the world—affected by rare diseases,” said Peter L. Saltonstall, president and CEO of NORD.

“Everyone knows someone with a rare disease. But, while many of these diseases are serious and lifelong, most have no treatment and many are not even being studied by researchers. This leaves patients and families without hope for a better future.”

A rare disease is one that affects fewer than 200,000 Americans. There are nearly 7,000 such diseases affecting nearly 30 million Americans.

World Rare Disease Day was launched in Europe four years ago and last year was observed in 46 nations. It is always observed on the last day of February. On that day, patients and patient organizations will post stories, videos and blogs online and host events to raise awareness of these diseases, which are often called “orphans”.

In the U.S., the coalition supporting Rare Disease Day includes patient organizations and advocacy groups, medial professionals and associations, government agencies, researchers, and companies developing treatments for rare diseases.

Rare Disease Day 2011 activities in the U.S. will include creating an online library of two-minute videos about specific rare diseases and how they affect patients’ daily lives. Also, patients across the nation will help NORD create a database of physician experts. Patients will share their personal stories through a survey hosted by NORD and the Pew

Research Center, and there will be a drive to enlist support for a new Rare and Neglected Diseases Congressional Caucus.

What can you do to Support Rare Disease Day?

- Tell Your Story
- Create a Video
- Write Your Reps
- Write a Blog or email your Friends and Families
- Organize a display at a local school or hospital
- Participate in an event near you
- Join NORD on Facebook and Twitter and
- Use your status to raise awareness for Rare Disease Day

“More than half of the people who have rare diseases are children,” Saltonstall said. “Challenges faced by patients and their families include delayed diagnosis, few treatment options, and difficulty finding medical experts. Many rare diseases have no approved treatment. Insurance may not cover treatments that aren’t approved. Also, treatments for rare diseases tend to be more expensive than those for common diseases.”

For more information about Rare Disease Day activities in the U.S., go to www.rarediseaseday.us. For information about global activities, go to www.rarediseaseday.org.

iPad, iPhone and iPod Touch App Reviews



App Name: Signing Time

Available for: iPhone, iPad and iPod Touch

Cost: \$4.99

Review: If your child is started to learn sign language or if your child likes Signing Time videos then he will love the Signing Time app. It comes with flash cards, games and videos from Signing Time and Baby Signing Time. At \$4.99 is a little costly since it only contains 6 music videos, but if you have a child who likes Signing Time, this app will make him very happy.



App Name: Baby Finger HD

Available for: iPad

Cost: Free

Review: With three modes (shapes and things, numbers and both shapes and numbers) every tap of the finger on the screen will bring a new surprise. This is a great first app for a child who does not have good fine motor skills. I personally like the shapes and things game. The bright colors and big shapes will keep your child happily tapping. Also, make sure you have the volume turned up so can laugh at the funny noises (baby crying, toilet flushing, etc).

Karen Bess

Mom of Aiden (3 years old)

Financial Statement

For the year ending December 31st, 2010

Income: \$21,361.66

- Donations / Fund Raisers:
- Conference Fees:
- T-Shirts:
- Interest: \$5.99

Total Income: \$21,361.66

Expenses: \$10,034.96

- Office Expense: \$511.77
- Conference: \$7978.19
- Fund Raisers: \$112.99
- T-shirts: \$1302.00
- Network for Good / Paypal: \$130.01

Total Expenses: \$10,034.96

Closing Balance: \$ 24,434.08

Fund Raisers:

1p36 DSA thanks those who continue to fund raise to support our organization.

Jeans Day @ CB Richard Ellis - \$1,430.00 Kajsa Farnsworth, parent of Brady (1p36)

1p36 DSA was picked as the organization to receive all funds from a Friday Jean Day @ CB Richard Ellis.

BD Donation \$1000.00 - Karen Bess, mother of Aiden (1p36)

BD gives donations up to \$1000.00 each year for the hours an associates donates time to an organization. With the work Karen did serving on the board, website and finances was compensated by BD giving 1p36 DSA a \$1000.00 donation.

Hillis Fundraiser - \$275.00 - Bartley and Tammy Hillis, parent to Caden (1p36)

Bartley and Tammy Hillis created and sold gifts to help support and assist

further research on 1p36 Deletion Syndrome. The amount was donated in honor of their son, Caden Hillis, who was born with 1p36 Deletion Syndrome and Left Ventricle Non-Compaction Cardiomyopathy. The Hills looks forward to one day knowing that the medical community is aware and understands this syndrome and can assist parents and families as they fight this battle and overcome.

Pajama Party - Havana Club - Sherry Culvahouse, mother of Kaylee - \$540.00

Article from caller.com by Mike Baird
Pajama Party raises money for children's genetic disorder
Retired Navy IT specialist and club manager celebrate birthdays in PJ's to help

CORPUS CHRISTI — Two men celebrating their birthdays with a pajama party Friday at Havana Club raised \$540 dollars for a genetic disorder that affects one in 5000 U.S. children born.

“It’s fun on my birthday and it’s a really good feeling to help the next generation,” said Tellie Willingham, retired Navy information technology specialist.

He and Havana Club manager Marco Lopez have hosted the fundraiser for several years.

The money helps fund research and educate the medical community about 1p36 Deletion Syndrome, said Sherry Culvahouse, mother of a two year old, Kaylee, who was diagnosed in Feb. 2009 with the syndrome. It’s a genetic disorder caused by a missing portion of the largest human chromosome, which represents about 8 percent of the DNA in human cells. Delayed growth, limited speech and mental disability are some possible affects, according to the 1p36 Deletion Support & Awareness website.

Casual Friday @ Blue & Co LLC, Carmel, Indiana - \$200.00, Jason Friedman, father to Lily (1p36)

As an accounting firm, casual Friday’s are few and far between! However, they came upon an idea where, depending on meetings for the day, associates can wear jeans on any given Friday. There is one stipulation: the associate must donate \$5 to do so. The names of organizations are co-workers are involved with either serving on boards, volunteering or just “pet projects” in a basket. A name

is drawn from the basket and when we collect \$200, we donate that money to the lucky recipient. Since September of 2008, we have raised over \$7,400 for various local causes.

Memory of Grandpa Kenneth Knepley - \$500.00 - Jean Knepley grandma to Alyana Lerma (1p36)

Alyana’s Great Grandpa Kenneth Knepley passed away and part of the memorials was a donation to 1p36dsa.

Melting Pot - \$700.00, Hornik Family - Friends of Steve & Karen Bess, parents of Aiden, 3 (1p36)

The Melting Pot in Richmond Virginia is constantly looking for ways to support the community and those that are less fortunate. Over the summer, they were dedicated to raising money for 1p36 DSA. During the months of July, August and September, the Melting Pot featured their most popular four-course meal, The Big Night Out Fusion. A portion of the proceeds from this menu was donated.

BD Fund Raiser - \$ 1380.00 – Karen Bess, mom to Aiden (1p36)

Karen Bess had her 2nd annual fund raiser at work to raise money for the organizations. Co-workers donated \$690.00 and BD match the amount donated.

Family Fund Raiser - \$440.00 Michelle & Jomy Mathew, parents of Wes (1p36)

Organized by Paul Ignatius, a group of caring, loving and supportive cousins got together and decided to donate a few extra bucks towards the cause.