



# The Blue Ribbon Tribune

Official Newsletter of 1p36 Deletion Support & Awareness  
Fall 2009

Welcome to the Blue Ribbon Tribune! This is the first issue of the official quarterly newsletter of 1p36 Deletion Support & Awareness. Here's what's inside this issue:

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## Introducing 1p36 Deletion Support & Awareness

Initially conceived in the Fall of 2008 and officially incorporated on March 9, 2009, 1p36 Deletion Support & Awareness (1p36 DSA) is a nonprofit organization that grew out of previous support efforts by many individual 1p36 parents. The organization currently consists of a five-member leadership committee comprised entirely of parents of children with 1p36 Deletion Syndrome. Terms for members of the initial 1p36 DSA leadership committee will last two or three years depending on the position. Elections for new leadership will be held after that to allow others to participate if they desire. Full bylaws concerning leadership will be made available soon. The members of the initial leadership committee are:

Ken Shirtcliff – President  
Phoenix Schaefer – Vice President,  
Public Relations

Nathan Hanson – Vice President,  
Internal Relations  
Karen Bess – Treasurer  
Carrie Daggett – Secretary

Now that the organization has been officially incorporated, several activities are going on now to further formalize 1p36 DSA's organization. The first is the formation of various committees to work on specific tasks such as fund raising, improving awareness and conference planning. Many 1p36 parents and family members will be invited to participate on these committees. If you are interested, please get in touch with Nate Hanson, who is responsible for member communication at [nate.hanson@gmail.com](mailto:nate.hanson@gmail.com).

The official website of 1p36 DSA has just launched and can now be found at [1p36dsa.org](http://1p36dsa.org). Please visit to read current

1p36 DSA news and see the formal bylaws governing the organization. You'll also find inspiring stories, news and information about 1p36 Deletion Syndrome that you can share with others.

Another big item is our first ever membership drive. We'd like everyone who is a part of the 1p36 family around the world to be an official part of 1p36 Deletion Support & Awareness. More details about the membership drive and how you can participate will be coming in Winter edition of The Blue Ribbon Tribune.

A five year plan of action is also being composed to give the organization direction and goals to work toward. A brainstorming session for items to

include in this plan was held at the third annual conference in Indianapolis in July. The completed five-year plan will soon be posted [1p36dsa.org](http://1p36dsa.org).

Lastly, all of the legal paperwork to submit our organization to the Federal Government as a 501(c)3 Charitable Organization is now complete. Ken Shirtcliff has been working closely with our legal team to have the application submitted in the next few weeks. What does this mean for 1p36 DSA Members? All contributions made to the organization in the year it is approved by the IRS will be recognized as tax deductible. This greatly increases the ability to seek out large corporate sponsors to fund the work we will be doing. It's an exciting time for our 1p36 family.

## **Locations Selected for Upcoming 1p36 Deletion Support & Awareness Conferences**



Since our last conference in Indianapolis, Indiana, proposals have been rolling in for venues of future conferences. A three-year plan is proposed so members can prepare to attend and save money for travel well in advance. Upcoming conference venues are:

- 2010 – Salt Lake City, Utah – July 30-August 1
- 2011 – St. Paul, Minnesota – Exact Dates TBD
- 2012 – Gatlinburg, Tennessee – Exact Dates TBD

Conference planners for Salt Lake, Nate and Melanie Hanson and their committee, are kicking things off on Friday, July 30<sup>th</sup>. To allow for more time for group interaction, they are planning on speakers in the mornings, less structured workshops and classes in the afternoons and optional activities in the evenings. Sunday afternoon will be left open as travel time for those who

will need to return home in time for the upcoming work week. Watch for more details about upcoming conferences on [1p36dsa.org](http://1p36dsa.org). For those interested in joining the 2010 Conference Committee, please email Melanie Hanson at [melanie.hanson@gmail.com](mailto:melanie.hanson@gmail.com). It takes a lot of organization to put together the conferences and many hands make light work.

### Third Annual Conference a Success



The third annual conference for 1p36 families, caregivers and supporters was held in Indianapolis, Indiana in July. There were approximately 36 families in attendance for a total of around 140 attendees. That's the largest group to attend a conference so far.

Speakers presented new information about the 1p36 Deletion Syndrome and its treatment. Panels discussed specific concerns and solutions families in the group have found. Attendees enjoyed a pool party and movie night together.

And best of all, families were able to network together and spend time supporting one another.

A \$50 gift card was given away as a prize to one lucky conference attendee. That winner was Karen West. Congratulations Karen! Enjoy your prize and thanks for attending the conference.

It takes many helping hands to make a conference this big successful. The following Individuals, corporations, volunteer speakers and donors were instrumental in the 2009 1p36 Deletion Support & Awareness Conference in Indianapolis, IN. We are grateful for your support and kindness towards our children and this amazing organization that brings hope to so many of our families.

Thank you so much to the following individuals for their dedication and sacrifices:

- Julie and Jason Friedman** – 2009 Conference Planning Committee Chairs
- Phoenix Schaefer** – Conference Planning Committee, Securing the Donated Funds for the Binders, Social Planning Committee
- Gavin Ross** – Conference Planning Committee, Sibling Workshop, Dad's Breakfast, Memorial Service Committee
- Kelly Turner** – Memorial Service Committee

**Robin Jones** – Conference Planning Committee, Sign Language Workshop, Social Planning Committee

**Debbie Sander** – For helping finish the gift bags Thursday night!

**Karen and Steve Bess** – Conference Planning Committee, all of your tips and tricks from previous conference, Binder Printing and for helping put together the binders on Friday!

**Carrie and Shawn Daggett** – Conference Video Taping and Helping put together the binders on Friday!

**Jeanne Spaletto** – For making the awesome Conference DVD with our children and their beautiful smiles!

**Toni MacDonald Hinkley** – For duplicating the Conference DVD and allowing each family to take one home with them.

**Carla Erickson** – For donating a portion of the speaker's gifts and conference gift bags and for staying up Wednesday night and putting them together!

**Sherryl Clifford** – For donating the toys for the 1p36 Babysitting Room and driving them down to the hotel on Thursday night.

**The Arnold Family** – For picking the toys back up and returning to the Cliffords!

**Angela Gallagher** – For donating the Office Depot Gift Card and Supplies

**Barry Shewmaker and LaTamia Briscoe**- Embassy Suites Downtown

**Bridget Davis and Anne Lustig**– Babysitting Volunteers

We had amazing and knowledgeable speakers volunteer their time to this year's conference. Many traveled very far to be with us: Washington State, Canada, Florida, etc. Thank you so much for making the time to educate our families. We learned so much!

Therapist Panel: **Amy Peterson**, Physical Therapist; **Marci Penner**, Occupational Therapist; **Krista Elston**, Speech Therapist; **Trina Easton**, Nutritionist

**Dr. Lisa Shaffer** – Signature Genomic Laboratories

**Gordon Homes**: Special Needs Financial Planning – Met Life

**Robin and Abby Jones**: Sign Language Workshop

**Dr. Kevin Bax**: GI Speaker

**Dr. Anthony Perszyk** – Pediatric Developmental Geneticist

We had an overwhelming response for donations this year. Both corporate and individual donors came forth with very generous donations in monetary support, discount services and donated goods. Thank you for your support of the 2009 1p36 Deletion Support & Awareness Conference. We couldn't have done it without you! In all of our fundraising efforts we raised over \$10,000. Not only did this fund this year's conference but will go toward future 1p36 DSA conferences and efforts.

**Accent (“Sybil” Terry Riley)** – Donated the money used for the Conference Binders

**Get Well Network**

**Office Depot**

**Roche**

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**T&T Promotions  
Therapeutic Resources**

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Steve Bess  
Fiona Zibell  
Fred Furia  
Carrie Daggett

### **Summer Fundraising Events:**

Read how 1p36 parents have been busy raising money for 1p36 DSA.

**Scrapbooking Party:** The Friedman family hosted a scrapbooking party. Total raised was \$1800.

**Tastefully Simple Fundraiser:** From main dishes to desserts, Tastefully Simple offers a wide variety of easy-to-prepare foods. There was over \$1,700 in sales and the profits for 1p36 DSA totaled \$342. Thank you to all who purchased Tastefully Simple products and special thanks to the Lyons family for setting up the fundraiser.

**Lily & Friends Backyard Flix Fundraiser:** was held July 17th by the Friedman family. It was a night of celebration, yard games, food, drinks, smores by the fire and a movie under the stars. Over \$3,000 was raised.

**1p36 Deletion Syndrome Car Decals:** Car decals were donated by friends of

### **Continuing Fundraising Events:**

Every time you shop at any of 700+ online stores in the iGive network, a portion of the money you spend benefits 1p36 DSA. iGive is a free service, and you will enjoy iGive's repository of coupons, free shipping deals and sales.

Create a personal account and searched

the Greene family. The car decals were sold for \$5 a piece to 1p36 families. Total raised \$220.

**Zoe's Tea Party:** A "Phantom Tea" was held by Gilman family. Individuals donated money and received a tea bag and Thank You card from Zoe. August 1<sup>st</sup> was designated the day to have the Tea Party since that was one of the conference days. This way individuals who donated would be enjoying yummy tea and could feel connect to Zoe who would be playing with her 1p36 friends. Zoe raised \$508 Canadian / \$459 US.

**Aiden's Family and Friends Fundraiser:** The Bess family reached out to friends and family to provide information about 1p36 deletion syndrome and ask for donations for 1p36 DSA. Aiden sent Thank You cards and a photo of himself to all who donated. Total raised was about \$3,000

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for what I wanted to buy and earned \$ for searching. Purchase any item and receive a % of the sale. Purchase an item within the first 45 days of the account being open and received a \$5.00 bonus.

Each time \$25.00 in donations is reach, 1p36 DSA will receive a \$25.00 check! \$100 has been raised to date.

Create your iGive account now at [www.iGive.com/1p36DSA](http://www.iGive.com/1p36DSA)

## Member Messages

Each quarterly newsletter will have a page dedicated to members who want to tell their story, share helpful tips or express their feelings to our 1p36 family. This quarter we have excellent submissions from Karen West, Kylee Ridge, Terri Smith, Kelly Turner and Debbie Sander. Thanks for sharing with everyone.

### Special Siblings

By Karen West



The stress of raising two children can be somewhat overwhelming at times, but when you have one typical child and another with 1p36 Deletion Syndrome, well, let's just say there's never a dull moment in the house!

When Tabitha was first born, we immediately noticed something was different with her. In the weeks to come, it became more and more apparent that my little girl wasn't just an ordinary baby. At her first doctor visit the doctor mentioned she had a heart murmur. I'll never forget, he said, "Everything looks great and you guys know to keep an eye on the heart murmur?" My mouth dropped to the floor. My husband's eyes

wide open...."What???"

Now looking back at how terrified we were just over a heart murmur seems so impractical compared to the mounds of medical issues Tabitha has faced since then.

And what about Bradley? My previous son who had always gotten my devoted attention over the smallest of things. Bradley was seven years old when Tabitha was born. Seven years as an only child. Seven years getting anything and everything he ever wanted. How was my spoiled child of seven years going to deal with have a sibling, much less a sibling with severe special needs?

As the years have gone by, my son has shined in his role as a child with a special needs sibling! He can now tell you about Monosomy 1p36, gastronomy tubes, and tell you how a Vagus Nerve Stimulator works. It hasn't been an easy road for him, I know. When Tabitha was about 6 months old he asked me, "How come you spend more time in Tabitha's room than mine?" I tried to explain to him that Tabitha needed a

diaper changed, or medicine, or something, but his sad little face made me feel like I was neglecting him. At times, I felt that there was no possible way I could give both my children the attention they both deserved. It is a balance that comes easier as time goes on.

With that being said, I wanted to share with you a perspective from a sibling of a 1p36er. Bradley, my son is thirteen years old and he wrote this:

The last six years of my life have gone by. In the year, 2003, my sister (Tabitha) was born. I was about 7 years old at that time. When I first held her in my arms, I saw something. I saw a bond. I saw a friend. But more importantly, I saw a new life not just for me, but for everyone in my family.

I remember saying three words to her. As I ran out of words, she would cry and cry. I knew right then, I would have a little sister who would be there for me. I remember my mom telling me the first time she (Tabitha) had a seizure. We were at home. She (Tabitha) made a face, and threw her arms out straight. When it was over, she would cry. At that point, we were 90% sure that something was wrong. Then, Tabitha was at Vanderbilt Hospital. We found out that she had something called a chromosome 1 deletion. She had 1p36 Deletion Syndrome. She soon needed therapy. She couldn't walk, she couldn't talk, and she couldn't eat the same way we do

either. So, the doctors put a Mickey button in her stomach. This is how we feed her.

For therapy, my sister goes to three different therapies. Physical therapy for exercise, Occupational therapy for moving her hands, and Speech therapy.

The more she did therapy, the more she could do. By age 4, she could say a few words, hold a few things, and with the help of her walker, she can take a few steps.

You know, a couple of things make me feel angry. I get mad when people say "retard" or "retarded" or when people laugh at my sister or any special needs child. But you know what? It's going to happen and it's going to hurt you. You have to teach that person right from wrong.



My sister is now 5 ½ . Her name is Tabitha Paige, the little girl who will teach you more about humans. I am her 13 year old brother, Bradley Tyler.

Isn't it so interesting to hear a sibling's perspective? I wish I could have gotten him to write more! In due time....



## **G-Tube**

By Kylee Ridge

Decisions are a major part of parenthood. Unfortunately, some decisions that go hand in hand with raising a child with special needs are a little more complex. Our daughter, Sarah, was admitted to the hospital five times between December '08 and March '09 due to chronic constipation and vomiting episodes. Each time they would insert an n/g tube and fill her full of golytely. Each stay lasted at least two days, a couple lasting even longer. During these constipation spells, Sarah also began vomiting uncontrollably. The doctors blamed the vomiting and her sudden lack of appetite on the constipation.

During one of Sarah's hospital stays, a nurse brought up the topic of g-tubes. She thought in Sarah's case it would be worth it for meds alone. With all of the vomiting and sudden aversion to having anything by mouth, medicine time became a nightmare and it was very rare that the medicine stayed down if we did get it in her. Of course, we now added very frequent seizures to our list of issues as she was not keeping that medication in either.

When we finally got in to have a consultation with the surgeon, Sarah had already lost six pounds. He said usually g-tubes weren't used without major feeding issues being present, but with her hospitalization history and her sudden loss of appetite, he thought it would be in her best interest. There were definitely people who advised us

against this invasive procedure, but they were not the ones living our daily struggle. As a parent, I felt like a failure when I could not coax her into taking her medicine, or when I would watch her vomit up everything I had just given her.

We finally decided to go ahead with the surgery, and I have to say it was one of the best decisions we have ever made. Sarah has not been admitted to the hospital since the surgery, which was performed in March of 2009. During this time she also received an eosinophilic esophagitis diagnosis, so we are not out of the woods yet with the vomiting and eating issues, but we are working on it. At least I can give her Pediasure on the bad days and not have to worry about her becoming dehydrated. Medicine time is no longer stressful, and Sarah's five year old twin sister even likes to help give her the meds through her tube. Our initial reason for getting the g-tube was to get Sarah all of her necessary daily meds, and luckily for us it happened to coincide with a time when she also needed it for daily nourishment.

I know this a decision that many families have to face. In Sarah's case it was absolutely the best decision we could have made. I would love to say that I hope none of you ever have to make this decision, but unfortunately I know that is not reality. Just know, that in the right circumstances it can be a life saving decision

## Looking Back

By Terri Smith

Fall is upon us, school preparations are in full swing and autumn weather threatens, and along with the blowing winds come moments where my thoughts fly back to the day when I got the call that gave answers to EK's delays, the ones that had had my husband and I flummoxed for most of a year: the low tone, the feeding difficulties, the obvious delays. And, like every other year when I start remembering, I wander back thru the pages of my blog and find the entry that spells out the reality of that day as though it were happening again.

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**November 11, 2005** Just finally catching up with some of the (too much) info we've been given, so I'm trying to drag myself out of lurkdom (here, online, in real life) & "get back on the horse," so to speak.

So...



We finally got a diagnosis for EK, which only means that we have a whole slew of new questions to be answered (of course). For those who want the big long technical part, this is it: 46,XX, ish der(1)t(1;16)(p36.33;q24.3)/CEB108/T7-,16PTEL05+). Its all perfectly clear from that, right??

Translation? EK has a 1p36 deletion, with a 16p trisomy replacement. Still confused? The very tip-top end of one of her Chromosome 1's is missing, and it has been replaced with a duplicate end of Chromosome 16.

What does it mean? Well, that's where things get fuzzy. They have a lot of information — well, not a LOT, but... — about a 1p36 deletion. Unfortunately, with each possible replacement, the specifics change, and they have no record of another 16q replacement. So we're kind of in blind territory.

Normal things they expect with a simple 1p deletion (no replacement) are: heart problems (enlarged heart, defects); increased seizure risk (50%); hearing loss over time; irregular testosterone levels; low muscle tone (tho virtually all children with this deletion will eventually walk); develop low thyroid (20%); degenerative eye

problems (cataracts, etc) developing over time; swallowing problems; slow growth; short stature; developmental delays; learning difficulties. Yeah. I'm sure there is more, but honestly, I have trouble keeping track sometimes. What to expect with a deletion and a replacement? No one can say for sure.

So, for the time being, we are seeing all the specialists to rule out things, and to get baselines on the other things we need to monitor. So far, she has been cleared by the cardiologist — no defects on exam, EKG, or echocardiogram. (YEAH!!) In the next month, she will be seeing an audiologist, an ophthalmologist, a peds ENT specialist, have cranial xrays, be screened by a birth-to-three program for developmental analysis, and and and.... Tuesday alone we were at 3 different drs offices (PT, peds, and cardiologist); plus it was flu shot clinic day, so we were back again that night for that.

The genetics counselor said we should go ahead and get her qualified for SSI disability, because she will qualify for it with this diagnosis. Honestly, it's not what I was expecting, and that took some time to get used to.

She is going to be one year old next week — my, how time flies! — and we are hoping she will be close to crawling by then! She can sit up if we sit her up, but she

can't get to sitting by herself (doesn't pull up at all), and has just started to commando crawl this last week (after 2 months of weekly physical therapy). She does play patty-cake, and peek-a-boo with the kids, and has started teasing them and then giggling when they react, so that's good. (The other morning she was watching her dad sleep, and she kept hitting him — once — in the face, then giggling while she waited for him to react... wish I'd had the video camera to capture that one!) She just started babbling this last month (says 'da' and 'ba' now, and blows raspberries of a sort); can't wait to find out if she has a hearing loss already and that is why she is so delayed doing that.

But, on the up side ... she's adorable, and happy, and easygoing, and a wonderful addition to our family! (Can't keep the kids away from her! LOL)

So. Back to your regularly scheduled programming. And hopefully I'll be back to a little more



normal, soon, too.

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And yet, it's now four years on, and that little girl who couldn't quite commando crawl is now on the verge of running. I got the call this morning from her ReadyStart bus driver that he'll be back again Tuesday morning to take her off to school. She talks and talks, and I even

understand a few words here and there – and she's good enough to repeat them for me, so I can catch up with her!

I know it's not a short road ahead, or an easy one; the road behind us has been long and hard, but seems to have flown by in retrospect. I love to imagine where she might be in another four years!

## **The Perfect Vacation Spot!**

By Kelly Turner

This year, Ryan's Ranch International, a nonprofit organization with the mission of enhancing families and enriching lives of children with significant developmental disabilities, began planning for 10 special-needs, family friendly resorts across the United States.

Ryan's Ranch will be a unique vacation spot for our families. Not only will the resort have universal accessibility, it will offer:

- 45 different therapies (HBOT, Hippotherapy, Massage, Aqua, etc)
- lakes custom made by Bill Dance the fisherman...children in wheelchairs can fish from the middle of the lake
- recreational activities for siblings and parents
- extra hands that will assist families
- zero entry pool
- sprinkler park
- physicians on staff to handle minor medical emergencies (such as seizures, etc)

- special menus for special diets
- accessible tree house
- universal playground area
- sensory suites and cottages

The first resort is slated to open in 2012 (depending on funding – they need to raise \$45 million) in the Mid South just south of Memphis in Lake Cormorant, Mississippi. Other cities that are being considered, but subject to change, are: Nashville, Tampa, Maryland's east coast, and Dallas Fort Worth area. Eventually the organization would like to go global with Ryan's Ranch.

For more information, their new website will be up and running soon: [www.ryansranch.org](http://www.ryansranch.org)

Just a thought:

After communicating with the founder of the organization, she confirmed that the main lodge will have a place for meetings. Wouldn't Ryan's Ranch be a GREAT location for an upcoming 1p36 DSA Annual Conference?

## Natural Laxative

By Debbie Sander, mom to Jacoby, 3 years

\*I am not a nutrition expert. I am simply a mother who will try just about anything to help her kiddo deal with the problems that arise with being diagnosed with 1p36 deletion syndrome.

Being a parent of a kiddo with 1p36 deletion syndrome, I'm sure that you are no stranger to the GI issues they endure, including constipation. Luckily for my little guy, his constipation isn't chronic. Sometimes Mother Nature just needs a little help. Since he takes meds for seizures and cardiomyopathy, I don't like to pump him full of chemical laxatives (although we are huge fans of Miralax), so I sneak flaxseed into his diet. Not only does it help regulate his digestive system, it contains nutritious Omega-3 oils, which

What are the health benefits of flaxseed? Unlike whole flaxseed, which can't be digested, milled flaxseed lets your body absorb the benefits of the heart-healthy Omega-3 oils. These oils are thought to lower cholesterol and prevent the arteries from hardening. And while more studies are needed, Omega-3 oils may be useful in treating irregular heartbeat and heart failure.

Along with being heart-healthy, flaxseed is great for keeping the digestive tract moving. It is a very compact fiber that makes the stool bulkier and easier for the body to move. Bulky stools and adequate fluid intake (preferably water) allow the body to eliminate waste more effectively and constipation can be avoided. Without enough fiber, the stool is small and clumpy, making it hard to

pass through the intestines.

### Cooking with flaxseed

--Add flaxseed to a food you habitually eat. Every time you have a certain food, like oatmeal, smoothies, soup, or yogurt, stir in a couple tablespoons of ground flaxseed. Soon it will be a habit and you won't have to think about it, you'll just do it.

--Hide flaxseed in dark, moist dishes. The dishes that hide flaxseed the best usually have a darkly colored sauces or meat mixtures. No one tends to notice flaxseed when it's stirred into enchilada casserole, chicken Parmesan, chili, beef stew, meatloaf or meatballs. For a 4-serving casserole, you can usually get away with adding 2-4 tablespoons of ground flaxseed. For a dish serving 6-8, use 4-8 tablespoons.

--Use it in baking. Substitute ground flaxseed for part of the flour in recipes for quick breads, muffins, rolls, bread, bagels, pancakes and waffles. Try replacing 1/4 to 1/2 cup of the flour with ground flaxseed if the recipe calls for 2 or more cups of flour.

These are always a hit at our house. Use your favorite type of apple.

### Apple flax muffins

¼ cup milled flax seed

¾ cup whole wheat graham flour

¾ cup white flour

½ cup sugar

2 tsp. baking powder

½ tsp. baking soda

½ tsp. salt

1 egg, beaten

1½ cups finely chopped apples

3 Tbsp. vegetable oil

½ cup milk

Blend dry ingredients together in a bowl. In a separate bowl combine egg, vegetable oil and milk. Add dry ingredients to egg mixture and stir until blended. Fold in apples. Batter will be thick. Fill well-greased muffin cups 2/3 full. Bake at 400 degrees F 18-20 minutes or until top springs back when touched. Makes 12 muffins.