



The Blue Ribbon Tribune

Official Newsletter of 1p36 Deletion Support & Awareness
Fall 2010

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



When my son Joseph was diagnosed with 1p36 Deletion Syndrome he was just over a year old. I remember how frustrating it was for my wife and I to know that something was wrong with our child but the doctors would just tell us that “all kids develop differently” and then as he got older no one had any real answers for why Joseph was the way he was. I

remember thinking that a year is much too long to have to wait to get a diagnosis for a genetic disorder that affects 1 in 5-10,000 children born. Yet as we talked to more and more families on the 1p36 Yahoo Group we realized that our story was not unique at all and that it seemed to be the norm rather than the exception. It was around this time that I knew I wanted to be more involved with helping the 1p36 community start a not for profit organization that could help support families and educate the medical community about 1p36 Deletion Syndrome.

1p36 Deletion support & Awareness officially started in the spring of 2009 and we received our 501(c)3 nonprofit status last fall, but the

education and support started long before. There are many parents and caregivers that have given and continue to give wonderful support and education through the Yahoo group, Facebook, and their interactions with their local medical community. The last year and a half have been a huge learning experience for the board of directors. We have had many phone conferences working hard to lay the foundation for an effective nonprofit that is at the forefront of information about 1p36 Deletion Syndrome and an organization that listens to our members and is able to educate, not only the medical community, but the nation about 1p36 Deletion Syndrome.

As most of you know, one of our current projects is to try to get a \$50,000 grant through the Pepsi Refresh Project to be able to educate the nation's medical community about 1p36 Deletion syndrome. We may or may not be able to get into the top ten

and get the funding from Pepsi, but the goal will not go away and we will find other ways to get the funding we need to accomplish our goals.

As our organization grows, one of the large challenges we face is to be able to use the many talents that are within the group. If you are talented in any specific area that you feel could benefit our organization please e-mail me at k.shirtcliff@1p36dsa.org. Whether you are good at fundraising, web design, writing, organizing, or anything else, let us know. If you have an Uncle, cousin, or friend who would like to help us, we would love to hear from them as well. We also want to hear from you about things you would like us to do or ideas you have that can help 1p36 Deletion Support & Awareness become the best organization we can be.

Ken Shirtcliff
President, 1p36 Deletion Support & Awareness

October Is Our Month to Win the Pepsi Refresh

1p36 DSA continues to compete for votes at www.refresheverything.com/1p36. We are competing with many other organizations for a fifty thousand dollar grant contributed by Pepsi. This contest is based on a popular vote with the top 10 submissions at the end of the month receiving grants.

We've competed during the months of August and September and done very well, but we've fallen just short of

being a top 10 vote getter. So we're going to give it another try with a new approach. First, encourage your friends to visit www.1p36dsa.org/maillinglist to sign up for a daily voting reminder. Then download printable stickers and other materials to share with your friends. We also encourage 1p36 families to spread the word to the media wherever you live. We have also partnered with other similar projects that will be voting for us all month. In

turn, we ask that you vote for them as well at <http://pep.si/c7kBwr>. You can also text your vote for 1p36 DSA by texting the message 101439 to 73774 (Pepsi).

As a little extra encouragement to get out the vote, one lucky person who signs up for daily reminders will win an Apple iPad. This tablet device has a 10 inch touch screen and room for all kinds of music, video and apps. So

sign up for reminders to vote and have your friends do the same. There's only one catch. In order for the iPad to be given away, 1p36 DSA must be awarded a grant in October. For the most up to date 1p36 Pepsi Refresh into go to www.1p36.blogspot.com.

Get out the vote. Help 1p36 Deletion Support & Awareness be a winner, and you may be a winner too. Visit 1p36dsa.org for details.

Spotlight on Kaylee Culvahouse



Kaylee's entrance into this world marked the commencement of a miraculous journey- a journey of challenges and obstacles, a journey of beauty, grace, and hope. She made her entrance with a small deletion on her 1st chromosome, and so began our family's walk with 1p36 deletion syndrome. Despite a small deletion on her 1st chromosome, Kaylee provided our family with multitude of blessings, trials, and lessons. Her small body arrived with feeding difficulties, acid reflux, infantile spasms a catastrophic seizure disorder, hearing loss, umbilical hernia, blocked tear duct, farsightedness in both eyes, and hospital stays at Driscoll Children's hospital in Corpus Christi. As always, Kaylee flaunted her feisty spirit and

persisted on to complete a two month duration of ACTH therapy a very strong steroid injections. We are blessed to say Kaylee's seizures finally were brought under control with ACTH therapy, a drug that gave Kaylee the upper hand on epilepsy. But to limit Kaylee's existence and achievements to the confines of a genetic condition would be the ultimate disservice to our little fighter girl and our God. Kaylee is a testament of God's faithfulness and timing. Kaylee is a beacon of light in a shadowy world of hardship. She is an illustration of perfection in her innocence and resiliency. She is a representation of all that is good. She is a daughter and a sister who has been the guide for her family and their faith on a walk into the unknown. She is an expert teacher on living each day and each moment in the present. Though her strides thus far have already been numerous, she undoubtedly has much more to share with this world.

So far, Kaylee has been seizure free from last Feb 09. We are truly blessed that she's been medically healthy...Praise God. Kaylee is a happy & loving two year old. We are so proud of her and all of her accomplishments...some big and some small. She's able to sit longer periods at a time sometimes over an hour depending if she's motivated by one of her toys. Kaylee can feed herself finger foods such as Cheetos, banana puffs, really anything she can grab. She's been very alert to her surroundings...very curious to see what's going on. We love how she's been making awesome eye contact with strangers and even tries to interact with them. She's always loved looking at immediate family but now she's been exploring out of her box. She's been weight bearing more on her feet without the need for her shoes which is a huge accomplishment for us. She's been sustain grasping her toys for longer periods now and will tolerate certain sounds like crinkling of foil. We are also blessed that Kaylee can now babble...she can say baba, mom, wawa, & rara. She tries to move her lips when we sing to her...too precious. It was like one day out of the blue while we were visiting Yellowstone National park she started babbling. We like to think it's the fresh mountain air that did it for her.

Kaylee spends 3-4 hrs a day in therapy including PT, OT, Speech, Developmental, Vision, Hearing & Nutrition on a weekly basis. We added a couple more therapies per week to her already hectic schedule. She now receives music therapy and cranial sacral therapy. Music therapy is one of her favorites. She loves anything that

lights up or makes sounds. She always heads for the drums and piano. She thinks it's funny when she bangs on things...she loves repetition. Of course, I have to sing to her when she starts getting cranky but if it motivates her then I'll do whatever it takes...even if I have to sing row, row your boat 50 million times. Kaylee still is not motivated to crawl at this time, but I know she's getting close. She has all the pieces down, but it's the matter of putting it all together.

During this past year, our family has witnessed the most incredible outpouring of love and support from our family, friends, and complete strangers. More kindness and compassion and unselfishness, then we could have ever, ever imagined. I have, along the way, also met the most magical children and families that I would have never had the opportunity and the privilege of meeting had it not been for this journey. I have watched with immense joy and hope, the children and families who are accomplishing many wonderful milestones, some small or big, but equally awesome accomplishments. I have also watched with equal pain and sorrow, the faces of families whose children would not make it. A year ago I would never, in my wildest dreams, have imagined having to watch parents and siblings and loved ones, say goodbye and journey forward in this life, without their precious children. That part of the journey I will never be able to reconcile.

Each 1p36 child is so unique and each one of them has his or her own time frame of when they will reach their next milestone. A certain few of these

children appear from the outside, to be flying through life and it's milestones, but many harbor within them, medical issues and impending obstacles, waiting for an opportune time to show their faces. Others fight every day, every moment, just to be here with families who would move mountains to keep them here with them. One thing they all have in common is that they are all brave mighty fighters. Our children indeed teach us so much about life and how to be grateful for the "little" things. I am forever grateful for my Kaylee "my little miracle.

A year ago, our family found strength in each other, as we united, with one goal and one goal only and that was to see this innocent child through the unimaginable. And here we are a year

later all of us all together taken to the edge once more and brought back because of the will and spirit of a tiny precious baby girl. Kaylee Ashlyn and her presence and entry into our family is what we have been waiting for all of our lives. She has changed us and shaped us and empowered us to be the people we are today. We give thanks to God for leading us, sheltering us and covering us in His amazing grace so we can proclaim once more, how incredibly blessed and how humbly thankful we are. No one knows what tomorrow will bring or the day after that, or what awaits us around the next corner but what I do know, is that for today, in this moment, we rejoice.

Sherry Culvahouse,
Kaylee's Mom

Conference Memories 2010

This summer was our family's first time attending the annual 1P36 conference. We jumped at the opportunity to attend in our home town because it didn't seem as daunting, financially or logistically, to make the short trip from Phoenix to Salt Lake City. When the conference began and I saw a room fully of faces which were before only familiar from online pictures, I couldn't believe we had not attended a conference sooner.

We originally planned on staying with family nearby and quickly booked a reservation at the hotel because we wanted to spend every minute available with our 1P36 family. I am a shy person. I spend most of my days

hanging out with Brady or behind my desk typing reports at work. But among these people, I instantly felt at ease, as if I had known them for years. It was truly like a large second family full of people who just get it, sometimes more so than our biological families can get it.

We watched as our son stole toys from anyone and everyone because they are exactly the kinds of toys he likes. We were inspired by Rachel Coleman's story and laughed as most of the kids watched the screen behind her rather than her live performance. Our eyes were opened to the wide range of abilities among these beautiful children. We clung to every word shared by the parents of older

children and marveled at what they have provided for their kids with little to no medical information or resources at the time. We felt stronger and more confident in our parenting, buoyed up by the shared experiences and support from the other families in attendance. And we felt strongly committed to attending

more conferences in the future. Thank you, thank you to the conference planners, 1P36 DSA board members and to those who fundraise to make this event happen.

Kajsa Farnsworth
Brady's Mom

Dodgeball Puts the Fun in Fundraising



On July 24, 2010, we hosted our 1st 1p36 DSA Dodgeball Tournament at Dewey's Beer Garden in Corpus Christi, Texas. The tournament was a ton of fun on an absolutely beautiful summer day. We raised an incredible amount of 6,590 and also brought public awareness in the process. Not only did we raise awareness of 1p36 DSA but we exceeded our fundraising goal as well. The energy of everyone there was amazing and more than we could have ever expected. We had such a good time that day from start to finish. We had 10 teams consisting of 6 players on each team who participated in the tournament....20 dollars per person. There was a cash prize for the winning team consisting of \$1,000 dollars. It was a wonderful feeling knowing we accomplished so much through one simple event, Kaylee's Game!

We had many generous people who donated their time and money to our 1p36 DSA organization. There were many walk ins who dropped by just to donate money and check out the excitement. We had complete strangers who came to our event just to share stories of their experience with 1p36 deletion. We were amazed to hear their stories...it was like they came out of the wood work somehow.

We had many volunteers and sponsors who helped make our event a big success. Pappa Murphy's donated 20 pizzas, friends at Dewey's donated all their water & Gatorade proceeds, one couple even made snow cones and donated all their proceeds to 1p36 DSA. In the end, the Crush boys team won the \$1000 dodgeball tournament and then donated \$400 back to our cause. We are so thankful for everyone's kindness and generosity.

We like to think that all the publicity we got prior to the event was our key to a success turnout. We had Kaylee's picture plastered on the headliner of Corpus Christi Caller Times, "Dodgeball Battles Disease." We had a

full size story on the front page of the local section to help bring awareness to our community. Our local TV station came to our home to interview us and take some footage of our family which was aired @ 5, 6, & 10 the day before the event. Beau was privileged to be aired on 3 radio stations which really helped promote our event. We also had caller times and Channel 3 news cover our entire event which was really awesome. We accomplished our main goal which was to bring public awareness to our community.

Our friends at Dewey's went out of their way to make this event a memorable experience. Dave the owner at Dewey's went above and beyond. Dewey's team wore bandanas that stated "Kaylee's Game" on them. They also went as far as to embroider a pink baseball cap with "Kaylee's Game" and "hope, love, & faith" on it...too precious. Friends at Dewey's ended it on a special note by celebrating Kaylee's 2nd birthday with a beautiful birthday cake, birthday encore, and balloons. It was truly a beautiful moment to have everyone there sing happy birthday to our little girl. It brought tears to our eyes to be surrounded by wonderful people who cared so much for her well being. This was truly remarkable and we are nothing short of honored and humbled by the overwhelming amount of support from everyone who was there for our little girl and all 1p36 families. It was such an uplifting and exhilarating event...words can't describe how we felt that day.



We'd like to sincerely thank each and every one for supporting our family and our passionate crusade who supports our 1p36 Deletion Support & Awareness non-profit organization. We'd also like to thank our sponsors, volunteers, friends & family for their generosity and support. And none of this would have been possible without the creativity, dedication, and hard work of my wonderful husband and awesome father, Beau and the support and hard work of our dear friends & family. Special thanks to our sponsors: Tony w/the Crush Girls, Whataburger, Jim & Terri Philomeno, Bob w/Schlotzky's, Pappa Murphy's, Eric, Val, & Codi w/1440 KEYS, Friends w/ESPN 1230am, Justin w/Ken bridges Audio/Video, Caller Times, Channel 3 news, The Crush Boys (1st place winner team) and Juan for photographing our event. Can't wait to do this again in the spring!

The Culvahouse Family