



A Parent's Perspective

TxP2P Quarterly Newsletter

TXP2P UPDATE

Laura J. Warren, TxP2P

First I must apologize for not getting a Spring or Summer Newsletter out - I'm afraid the conference planning and my work load got in the way. We are working on a solution to this for the future but please don't think we dropped you off our mailing list - there just wasn't a newsletter!



Second, we have some **great news - we received a grant to pursue the transition program we have hoped to start for many years** - the Pathways to Adulthood Center. TxP2P and Texas Children's Hospital and Texas Association of Pediatrics received a federal grant to work on a Texas Medical Home Collaborative and to launch the TxP2P Pathways to Adulthood Program. Through this grant, TxP2P will provide emotional support, information, and a way to take action to begin planning and building for the future for families of children with disabilities and special health care needs. We will also disseminate information on transition, including employment options, collaborative and positive home settings, and social opportunities and networks via mail, email, website, and calls to TxP2P office. These tools

will be based on a review of models around the country and what services and supports are available in Texas. We will offer 1-1 matches for transition support and create local Transition Action Groups (TAGs). We will provide local 1-day workshops to parents and professionals. We also plan to train facilitators for Person-Centered Planning and social networks. We will continue to inform parents about transition via the annual conference. For more information, contact Rosemary Alexander (Rosemary.Alexander@txp2p.org) or Cynda Green (Cynda.Green@txp2p.org) or call 866-896-6001 or in Austin 458-8600.

The other big news is that **our conference was the biggest we've ever had**, with almost 450 attendees. When you add in the speakers, exhibitors, volunteers and children, we had over 700 people involved. All seemed pleased with the sessions and our wonderful speakers (who all volunteered their time) and exhibitors with their door prizes and the goodies at their tables. The kid's activities were bigger (if that's possible after last year) and we outgrew one room for our Family Gathering. We gave out the first ever "Paying It Forward" awards to 2 winning stories (see page 2) and I was surprised and then overwhelmed to find that the TxP2P staff, unbeknownst to me, named the awards for me and announced it at the conference. It was quite an honor as well as a huge surprise. Thank you all! Paying it Forward awards will continue next year so watch for an announcement at the beginning of the year for a call for stories!

And on to the fall and HALLOWEEN! We are partnering this year with a wonderful volunteer, Marty Barnes, and her CLU Campaign to get the word out about the **Trick or Treat Project**. You can read more about it on page 7 but it is simply a way to allow kids who cannot eat candy to participate in Halloween and have fun alongside their friends and neighbors.

And finally, we are just around the corner from **the start of the 83rd Texas Legislative Session** (January 8th, 2013). It is shaping up to be another difficult session where Health and Human Services could experience additional cuts similar to the last session. If you would like to learn more about the legislative process and how you can have a voice, check with Linda & Amy Litzinger, who will continue to train parents, self-advocates, and other interested parties to testify before various committees and the legislature. Learning to effectively advocate, share your story and affect legislative change is the cornerstone of our grant from the Texas Council for Developmental Disabilities. You can attend a training to learn more about the legislative process or to become a trained advocacy volunteer. For more information, contact Linda at Linda.Litzinger@txp2p.org at or Amy at Amy.Litzinger@txp2p.org. For additional information on the key interim charges for the House and Senate that could have an impact on people with disabilities, go to Interim Charges 2012 (http://www.txddc.state.tx.us/public_policy/82nd_Interim_Charges_2012-04-06.pdf).



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2012 Paying It Forward Awards Parent to Parent - Darlene Seaman

My daughter, Kaylee Rae, was diagnosed with bilateral generalized polymicrogyria and epilepsy when she was four months old. We knew something was going on for a while but wasn't sure what it was. At four



months old, she was not tracking, holding her head up, making sounds or much of anything. My mother, Darlene

Seaman, is the one who really helped me figure out what was going on. She lives a few hours away from us but she spent many hours listening to me on the phone talk about Kaylee's problems over and over. Our pediatrician decided to send us to a neurologist but we couldn't get in to see him for two months. When I told my mom this, she called the neurologist office and somehow got them to see Kaylee in two days! I think getting in

this fast is what has helped my husband, Kaylee, and I out the most. The neurologist sent us to the hospital because Kaylee was having episodes that sounded like seizures. I was devastated.

A week later, it was time to hear the diagnosis. We knew something was wrong but were not prepared to hear what the doctors actually had to say. My mom drove the few hours so she could be with us when they told us the diagnosis that Kaylee's brain did not develop correctly and they didn't know if she would develop anymore. They couldn't tell us much of anything. I am so glad that my mother was there by my side for the hardest moment of my life.

Since the diagnosis, my mom has helped out in so many ways. She drove down to be here with Kaylee and me when Kaylee had her first eye exam and was diagnosed with cortical vision impairment. She went to the emergency room with us when Kaylee was having seizures that we could not control. My mother has found many sensory toys that she felt could really help Kaylee develop. She is constantly thinking of new ways and things that can help Kaylee develop and learn to hold her head up. She talks to me every day about the

things we are going through and always offers a helping hand. I am so lucky to have a mother that is willing to help me out so much. She has put a lot of time and effort into helping us. She even set up a private lesson with her yoga instructor so I could learn how to do some yoga on Kaylee to help her with her overall muscle tone. My mom will continue to make sure Kaylee makes it. She is constantly talking to people she



knows and telling Kaylee's story to everyone. She has really helped me accept Kaylee's diagnosis and figure out the best way for Kaylee to be Kaylee. I love her so much for everything she has done for us.

The Goodmans

Our journey didn't begin the way most do. The invaluable support we received did not come from a doctor, a nurse, or even a well-meaning family member. No, our support came to us in a crowded room at an adoption agency as our angel, Jeannette, placed our six month old son into our arms.

We were new parents that day. We had no idea what we were doing. We were scared. We were overwhelmed. Suddenly, in the course of a few hours, we were the proud parents to a six month old son who had many medical needs.

Yet, the Goodmans were there, every step of the way. They answered any and all questions we asked. They called to check on us. They gave us support, advice,

and even hugs when we needed it. And the unbelievable support we received did not stop there.

A week after Matthew came home, we received an email from Jeannette asking for prayers for



a baby girl. We started praying. Over the next six months we kept up with this baby. We followed her recovery through three surgeries. We anxiously awaited news that

a forever family had been chosen for this baby girl. And as time went on, we realized God had called our family to be the forever family.

Six months after we first met the Goodmans, as they placed our son into our arms for the first time, they blessed us once again. They placed our daughter into our arms. Autumn also has medical needs. The Goodmans still answered all of our questions. They encouraged us. They supported us.

And a family relationship blossomed. Weekly phone conversations calm any fears we may have. The Goodmans join us for doctor appointments. They are a vital part of our family we cannot even begin express our gratitude for. Over the past twenty-eight years

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2012 Paying It Forward Awards - The Goodmans Continued from Page 2

they have fostered over 200 children, many with special needs. Each time a child enters their home they are welcomed with love and support. No one ever leaves their home a stranger. They keep in contact with their adoptive families when possible. They take an active role in being a support system for anyone and everyone.

Aside from fostering, the Goodmans volunteer for many different organizations including the low birth weight center, the Aphasia group, and many more.

It is people like the Goodmans who make the world a better place. They give their hearts to anyone in need.

On this special journey we meet a lot of parents and professionals

who live in a special world. Some make our lives better. Some confirm our deepest fears. All leave a place on our hearts that remains forever.

The Goodmans are different. They don't simply leave a mark. They change you. They make you want to be better. They are angels in this world.

Miscellaneous Texas Services

Why Get the Flu Vaccination – A recently published study in Pediatrics, “Neurologic Disorders among Pediatric Deaths Associated with the 2009 Pandemic Influenza,” found that a large percentage of children dying from complications related to 2009 H1N1 virus infection had chronic neurologic disorders. **336 children died from the 2009 H1N1 Flu – 227 of those had special health care needs!** Your child is at risk if he/she has any of the following conditions:

- Asthma
 - Kidney disorders
 - Liver disorders
 - Morbid Obesity
 - Neurological and neurodevelopmental conditions including disorders of the brain; spinal cord; peripheral nerve; and muscle such as cerebral palsy, epilepsy (seizure disorders), stroke, intellectual disability (mental retardation), moderate to severe developmental delay, muscular dystrophy, or spinal cord injury
 - Chronic lung disease (such as cystic fibrosis)
 - Blood disorders (such as sickle cell disease)
 - Heart disease (such as congenital heart disease and congestive heart failure)
 - Metabolic disorders (such as inherited metabolic disorders and mitochondrial disorders)
 - Weakened immune system due to disease or medication (such as children or adolescents with HIV or AIDS, cancer, or those on chronic steroids)
 - Endocrine disorders (such as diabetes mellitus)
 - Receiving long-term aspirin therapy for chronic disorders
- More information, http://www.cdc.gov/flu/pdf/freeresources/updated/chronichealth_fluguide_brochure.pdf

Video Monitoring Available from Plano Company

As technology has evolved, so has the ability for parents of children with disabilities or special health care needs to monitor them via state of the art video monitoring. Video monitoring would be especially important for children who have attendant care at home or who may be left alone for short periods of time. Plano, Texas based Pro-Active Security Monitoring Systems, Inc. (PSMS) is a new leader in providing such video monitoring services to families in Texas.

PSMS provides a state of the art cost-effective internet viewing experience that is secure and the highest of quality. Working and busy parents can always be near. For a low monthly fee, PSMS services include:

- The installation of our video monitoring equipment,
- secure password protected viewing,
- live viewing via Smartphones, iPads, laptops and other means of internet connection,
- the ability of parents to determine when they want to turn on and off the streaming,
- reduced pricing for TxP2P members, and
- 10% of all payments from participating TxP2P parents donated back to TxP2P.

For additional information, please call: Ron Baron, President, ron@proactsecure.com

PRO-ACTIVE SECURITY MONITORING SYSTEMS, 972-596-7040, www.proactsecure.com, License No: B17382

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Please remember to sign up for TxP2P Listservs. Contact Susan.Prior@txp2p.org if you want to join the Advocacy, ADD/ADHD, Autism, Bipolar, Dad's, Homeschoolers, Medical Home, NICU, Transition, or local area Listservs (Austin, Bryan/College Station, Coastal Bend/Corpus Christi, Dallas/Ft. Worth, Houston, San Antonio, San Marcos, Rio Grande Valley, & Waco/Temple). **We recently added the following listservs: Spanish, Amarillo, El Paso and Medicaid Waiver.** Contact Laura@txp2p.org to discuss moderating a new listserv for us.

Save our trees and a little money - get the newsletter via email! It prints out well or is easy to read as an email. If you are currently getting this by mail but would read it as an email or print it out, please contact Susan Prior (512-458-8600 or 866-896-6001 or Susan.Prior@txp2p.org) & ask to receive the TxP2P Newsletter via email. If you leave a voice mail, please remember to give us your email address. Thanks!!

Transition to Adulthood: Person-Centered Planning & Personal Networks (Part 2 of 2 - Part 1 is in 2012 Spring Newsletter)

Rosemary Alexander, TXP2P

PART 2. PERSONAL NETWORKS

There's nothing like the panic we parents feel as our children approach graduation from public school. We all wonder if our children are prepared to succeed in post-secondary education or a job, live independently, and have friends; we wonder what supports for assistance and safety are available. These concerns led me to gather a group together to do person-centered planning for my son Will when he was 20. I also became a person-centered planning facilitator and have had the wonderful experience of facilitating a variety of groups for planning an individual's future. But as I gained experience with PCPs, I began to worry about how these plans would be carried out. Most families feel overwhelmed when facing transition and may lack the resources to carry out a plan. So I began to think about how to extend the PCP group to become an on-going support. Then it struck me that personal networks would provide the structure for this on-going support. The idea of personal networks comes from a parent organization in Vancouver called PLAN (Planned Lifetime Advocacy Network, at www.plan.ca). Their book, *A Good Life*, describes parental fears for children with disabilities and then presents a tool for supporting a person at risk of isolation. Here are words from *A Good Life*: "A Personal Network is a team of people who have come together for one single purpose: to befriend, support, and advocate for the person with the disability. It's their job to worry, to oversee, and to plan in advance, to anticipate, to 'be on top of.' A healthy Personal Network is one where all members of the network are in touch with each other. They coordinate their support. They assign responsibility among themselves." "A Personal Network is a group of men and women who voluntarily commit to support a person who is at risk of being isolated and vulnerable by reason of their disability. Each person of the network has a relationship with

the focus person and with every other member of the network. Through their relationship they offer support, advocacy, monitoring and companionship." "The best guarantee of a safe and secure future for a person with a disability is the number of caring, committed friends, family members, acquaintances and supporters actively involved in his or her life." Will's PCP group turned into a network that still meets now, 10 years later. The group has met many times just to have fun: we eat a pot luck, drink some wine, talk and catch up on our lives. Will is always present and seems to enjoy each person: he falls over one's feet, spills another's wine, draws another around the house by the hand, or sits close beside another. We always update the group about Will's activities and well-being, and they have all gotten to know each other and Will. But gradually, as the group has matured, the members have become more aware of their responsibility as a personal network for Will, the work of building a web of support for the day when we parents are less active or no longer available. So they have begun to learn more about Will's needs and assets and to see distinct roles for themselves. One member knows best about Will's daily care, medical needs and communication - that area will be her specialty. Another has a financial background and is best suited to watch over Will's resources. The parent of another child with disabilities is part of the group and knows how to manage the CLASS program. Finally Will's brother, who has been active in the network from the beginning, has stated that with the network's support, he is willing to be Will's guardian. You can imagine how excited and reassured we parents feel about this development. Another TXP2P parent, Denise Sonleitner, has started a network for her son Maverick and has told me: "We started a person-centered plan group for Maverick in elementary school. PCP's are a

great tool, but I had bigger concerns looming about Maverick's future, when his dad and I could no longer care for him. People wanted to help in some way, but none of us knew how. When I heard about personal networks, I decided to give it a try. The best thing to result from having a network is feeling hopeful about Maverick's future. Creating a community of people who come together for one purpose (i.e. Maverick) and are over time becoming closer, more cohesive, and more vested in Maverick's future."

Getting Started

When parents hear about networks, they are intrigued by the concept but always ask: Who can I ask? How do I ask? Why would anyone join? One way to answer "Who to ask?" is by looking at the people in your life. Think of friends or relatives who've said, "Let me know how I can help." It never seems to go beyond this offer, but at least the comment does show interest and willingness. Being a network member will provide those who have offered a way to help in a safe, open environment, where it's okay to ask questions and possible to organize the how to's. Think of people you know who are young and uncommitted or older and just retired, people with a bit more time and effort available to spend on a "cause," maybe even people who are searching for a network for themselves. Or maybe another parent—I'll be on your network if you'll be on mine! Here's a list to spark ideas:

- Family friends, relatives, siblings
- Your child's friends, peers at school
- Church members, neighbors
- People in a club, interest group
- People at work
- Retirees
- Other parents
- People who work with your child or have worked with your child in the past

The question "How do I ask?" might be answered by looking at it as a request like for any other

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volunteer opportunity. When I asked my sister-in-law, who has served on many community boards, to join, she wanted to know how much time it would take. That led me to write an invitation explaining the concept of a network, what time commitment it involved, and how each person might contribute.

“Why would anyone join?” brings up the fear, what if a person I ask says No! A Good Life tells us to never take it personally if we are turned down. Just remind yourself that the person you asked may be too busy right now to commit. Another way to look at this question is by describing the network as something that will be positive for all participants, instead of asking people for help because we feel needy and overwhelmed. Taking a page from A Good Life, learn to describe your child in positive terms: instead of saying Will needs help eating, dressing and in all life areas, I explain what people will learn from being with Will about non-verbal communication, living in the moment, humor, and unconditional love.

I have observed that networks expand the energy, resources, ideas, and community connections available from one or two parents to a whole range of people. A network can give back to a family the hope that often leaks away through years of feeling isolated, losing services, hearing about the deficits of your child; the network gives a family the sense that there really are people out there who care, who will share time and effort, who are ready to learn and assist.

A network might be 3 people for someone who doesn't like crowds or 50 for someone who loves a party. It might be a group focused on just one issue, set up for a limited amount of time; for example, a network could be set up solely to help a person find a job or transition to life after graduation or buy a house, then disburse until another time. It might be focused on social opportunity; a shared on-line calendar would be the perfect tool to schedule outings for several in the network

to accompany the focus person to the movies, meals out, or days in the park. A network might appear spontaneous to the focus person who doesn't want anyone to plan his or her social life. A network looks different for every focus person.

What can you do now, at whatever your child's age, to promote the possibility of creating a network someday?

- Start to share your life with others.
- Encourage your child's interests and hobbies, which can become a link to a group.
- Encourage your child's social skills.
- Learn to describe your child in terms of his or her gifts and talents.
- Talk to people about your child's gifts.
- Start to share your vision of your child's future with people who are important in your child's life.
- Quit thinking you have to do it all yourself!
- Let go of being the total parent, the perfect parent!
- Become the learner.
- Make time to develop your own relationships.
- Open up your child's schedule and your own to make time for friendship.
- Let go of the necessity of being present at every social occasion. Maybe someone else can provide the supports that you usually provide for your child.
- Have faith in your child.
- Have faith in your community.
- Look for new communities to replace the ones that have let you down.
- Find ways to become optimistic about the future.

What if you are interested in starting a network for your child right away? Here are a few suggestions:

1. Order the PLAN book A Good Life and read it. Try www.amazon.com or other used book dealers or go to the PLAN website, <http://store.planinstitute.ca/> and click

on Courses and Products. A Good Life is at the bottom of the page.

2. Get in touch with me at TxP2P, rosemary.alexander@txp2p.org, or 866-896-6001 or local to Austin, 458-8600 and I will talk to you by phone or meet if possible to talk about how to get started.

3. Stay tuned to the TxP2P Pathways to Adulthood Program for future developments regarding networks.

4. Go to The Arc of Texas website (www.thearcoftexas.org) and click on Microboard Collaboration at the bottom of the home page. A Microboard is a personal network that has been incorporated as a non-profit. Someone from The Arc will facilitate a PATH planning session to start the group and Arc personnel will guide you through the process of forming a Microboard.

Encouragement to change your perspective

Our lives as parents of children with disabilities are often spent defending, fighting, advocating, searching, worrying, learning, pushing and pulling; we become strong and tough, informed and able. And yet a time arrives when we must say, enough. I found that as my son Will grew up, I began



to see him as okay the way he is. Of course, I continue to seek ways for him to learn and grow, but I have begun to think of him as a person in his own right, with gifts, talents, quirks, a strong personality, almost a finished product, beyond my control! I am ready to turn to others, to share my child, to let my child go into the world, to see what others have to offer him and what he has to offer others. And that's where Will's network comes in - it provides a safe way to make that transition. We can begin to imagine a life for him that is safe and enriched but in which we, his parents, are not the main force in his life, where others are available to him for love, fun, care and concern. Starting to think about networks can be the first step toward that new life.

In Memoriam

Our children have many different disabilities and special healthcare needs. All too soon, some of us may grieve our child's death. All of us here at Texas Parent to Parent are deeply saddened when we hear of a family's loss. We want to share our condolences to our TxP2P families who have lost a child recently.

Holly Alaniz, Sandra Alaniz & family

Dominque High, Maria High & family

Yolanda Iris Flores, Yolanda's family and sister, Olga Astorga

We have resources available for bereavement and there are groups in most areas which we are always willing to find for you. You may continue to receive the newsletter for as long as you like. We do have trained volunteers whose children have passed away and are willing to be matched as needed.

With deepest sympathy - the staff & volunteers of Texas Parent to Parent

Christina Graduates

Cristina has finished high school, and naturally, we marked the joyous occasion with a party. In fact, we did a lot of celebrating throughout her senior year. The highlight of Cristina's high school years was being the manager of the cheerleading team. Of course, like most girls who tryout but don't make the squad, she would have been even happier being a full-fledged cheerleader. But year after year, she went through tryouts unsuccessfully.

Although it was disappointing to Cristina, I consider it a fine example of inclusion: she was given the chance to participate in a normal high school ritual (cheer tryouts), and she was given no special treatment or consideration. When she didn't meet the objective standards, she suffered the disappointment of not making the squad just like numerous other girls who do not have disabilities. She was welcomed with open arms, however, in the role of cheer manager, and the coach even provided her with a previous year's cheerleading uniform for free.

Thus, it was no surprise that our first celebration of her senior year involved cheerleading. Cheer tryouts happen in the spring for the following school year. When Cristina tried out at the end of last year, she was named cheer manager for the junior varsity (rather than varsity) squad for the upcoming fall football season.

An exciting thing happened over the summer, however. Cristina matured a great deal, and her cheer coach noticed. Showing the coach's characteristic flexibility, she began inviting Cristina to

cheer for the varsity football games and to attend some varsity cheerleading team dinners. Cristina even traveled with the varsity squad to the playoff football games, and she was thrilled!

This year also saw Cristina getting her first paid job. She works 6 hours a week, and it has been a good introduction for her to the world of work.

Perhaps the most momentous event occurred when Cristina, without consulting us, invited a young man from her Special Education class to prom. He said yes, and his parents also gave their blessing. Cristina and her date were sufficiently mature that they dined alone on prom night. Indeed, I dropped them off at the front door of the restaurant, they went in and requested a table, perused their menus, placed their orders, and enjoyed their meal—without any supervision. They could not have been more proud to be so independent.



(Unbeknownst to them, I indulged my protective instincts by sitting in the restaurant's bar while they dined.)

We also dropped them off at the front door of the prom, they got their fill of dancing, and when they'd had enough, Cristina texted us to let us know they were ready to be picked up. Witnessing how

Ashley Sanchez, TxP2P Volunteer

well she handled herself that night was for me the highlight of her senior year.

As with any parent marking a milestone event, we can't help looking back with pride and some amusement. When our children are newborns, we tend to have dreams for them, worries about what their futures hold, and some preconceived ideas on who they might be. The amusement comes from realizing that our children have their own ideas on who they are, and so much of the joy of parenting comes not from micromanaging their paths but from witnessing (with immense pride) them forging their own paths.

The questions remain on what Cristina's future holds. Right now, we'll simply take things one year at a time. She will attend our school district's Plus-18 program (the program for students, ages 18-22, who have disabilities) which is housed at the community college nearby.

Cristina will continue her paid employment and will seek additional hours. If she decides to change jobs, the school district can assist her with job coaching.

She would dearly love to drive, but we don't think she will have the skills necessary to do so. She also very much wants to live on her own or with a roommate, and that is a goal that we think is more attainable, although at this point we're not sure what those living arrangements will ultimately look like.

What we do know is that it will continue to be a privilege to watch Cristina finding her own path. I'm sure we'll have much to celebrate.

Redefining Normal

One of the hardest things I have had to learn while raising my daughter with special health care needs is to redefine normal. This is something that all of us struggle with everyday. Texas Parent to Parent helped me put this into perspective many years ago and taught me that I needed to mourn the life that I had planned and all of the expectations that I had made for my child. It really helped me in my journey to understand that I was dealing with loss (not the loss of a life, but the loss of the life I expected) and that until I let myself mourn that loss, I would not be able to move past it.

I soon quit focusing on what could have been, what I was missing, all of the things my child could not or would not do and instead I started focusing on what she could do. I was able to see things in a much different light. Don't get me wrong, I still have bad dark days, but I am able to process those feelings now and I am able to focus on the good in life rather than dwell on the unfair.

Holidays are always hard for parents of children with special health care needs. There are so many traditions from our own childhood that we want to pass on to our children, and sometimes we just can't. Many of our kids deal with special diets. Some are 100% tube fed, some are on special diets, and some become so sick easily with new foods. A lot of the TYPICAL holiday traditions are focused around food. One such tradition is coming up - Trick-or-Treating on Halloween.

I LOVED Halloween as a kid. I could hardly wait to get my costume ready and hit the streets trolling for candy. I remember each year my sister and I would go to as many houses as we could in the time my parents let us go. Then we would return home with our plastic pumpkin pails filled with sweet treats. She hated chocolate (I know - I could never understand that either) and I LOVE chocolate. We would dump out our pails and I would trade her all of my starburst and skittles for all of her chocolate. We would eat as much as we could before our parents would pull the pails from

our hands and we could collapse in a sugar coma. Then we would be rationed out a couple of pieces a day until the stash was gone.

I always looked forward to taking my child Trick-or-Treating and watching as he or she would show the same excitement I remember. My daughter suffered a trauma a birth and is not able to eat any food by mouth. All of her food is provided through a g-tube. Sure, I could still take her Trick-or-Treating, but it just never felt right to me. I don't want to take her out to get all kinds of goodies to only go home and take them all away. Not only that, but then the goodies end up being eaten by myself and her dad (we like it, but we don't need it).

As Casey got bigger I started taking her to a few neighbors' homes that know her. They would have stickers or little toys just for her. Things she could keep when she got back home. Casey loved this. She would hold on to her treats with such pride as we left each house. After doing this for a few years I realized that there are so many other kids out there just like Casey. I wanted to find a way to make Halloween more accessible to ALL kids.

Last year I created the CLU Campaign & we launched our Trick-or-Treat Project (<http://www.clucampaign.org/projects/halloween/>). This year we have teamed up with Texas Parent to Parent and Mommies of Miracles to take this project to the next level.

What is the Trick-or-Treat Project?

It is really quite simple. By simply adding (no one has to get rid of candy) a non-food treat (stickers, pencils, toys, etc.) you are making a HUGE difference for some pretty amazing kids. In order to let people know that you offer non-food treats the CLU Campaign offers a few tools. You can download and print out a door decal. Place the decal where

Marty Barnes, TxP2P Volunteer

it is visible to trick-or-treaters to let them know you have non-food treats. You can also register your address (no personal information required). Anyone can pull up the CLU Map and see all participating home nearby. Kids can map out their trick-or-treating route before they even leave the house. We also offer a smaller decal that kids can wear. When you open the door and see a kid with the decal on their costume, you know that this child prefers a non-food treat. That's really it. There is no cost, and the non-food treats are about the same cost as a bag of candy (some can be even cheaper). If you are in the Austin area, local Coffee Bean and Tea Leaf's will have these available in their stores as of October 1st while supplies last.

Why should you participate in the Trick-or-Treat Project?

The most obvious reason is for the kids of course. Making a difference in the life of kids with special needs is beyond rewarding. There are other reasons to participate as well. Non-food treats don't go bad. You are not left with a bunch of candy that you end up eating yourself. Instead you can store the non-food treats with your holiday decorations & reuse the left-overs next year. The cost of non-food treats is NOT more than candy. Kids LOVE non-food treats as much as candy (some teenagers may not, but the general

population is just as happy – if not more so with a non-food treat as they are with candy). We provide ideas for non-food treats, links to the locations where these types of treats are generally available, as well as lots of other fun Halloween ideas on our Trick-or-Treat page.

We are not candy haters (I personally LOVE candy). We are not asking people to ditch candy all together. If you want to ditch the candy, that's your choice. All we are asking is for people to add a non-food treat to their Halloween goodies.



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Texas Parent to Parent is committed to improving the lives of Texas children who have disabilities, chronic conditions, and/or special health care needs. We accomplish this by empowering families to be strong advocates through parent to parent support, resource referral and education, and by educating professionals about the unique needs of our children.



Trick or
 Treat
 Project
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CONFERENCE CALENDAR

DATE	NAME OF CONFERENCE	CITY	REGISTRATION INFORMATION
Friday, Oct. 26 to Saturday, Oct. 27, 2012	<i>Including You Conference: Building Inclusive Schools Together</i>	University of Houston, Houston	For more information: http://www.fathersjoy.org/including_you/home/
Thursday, Nov. 1 to Saturday, Nov. 3, 2012	<i>NAMI Texas Annual Conference: Partnering for Change, Building the Future</i>	Sheraton Hotel at the Capitol, Austin	For more information: http://www.namitexas.org/newsletters/201204-2012conference.shtml
Friday, Nov. 2 to Sunday, Nov. 4, 2012	<i>7th Texas Chargers Annual Retreat</i>	Camp Allen, Navasota	For more information: http://www.texaschargers.org/events.html

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