



A Parent's Perspective

TxP2P Quarterly Newsletter

Please check out the new website for Texas families with children from birth to 5 years of age

www.parentcompanion.org

TxP2P Update

Laura J. Warren, TxP2P Staff

What an amazing weekend! The 2014 10th Annual TxP2P Parent Conference took place June 13th – 14th at Embassy Suites and Convention Center in San Marcos. Throughout the weekend, over 90 experienced speakers shared information and led discussions on over 84 topics. Over 525 conference attendees took advantage of informative sessions including the Teen Summit! New and old friends of all ages participated in the Family Gathering on Friday night, enjoying the photo booth and performance by Sara Hickman. Hope you can all join us next year on June 12th & 13th back in San Marcos.



We also just had our annual fundraiser, the 10th Annual Vine to Wine Reception and honored the following outstanding friends:

TxP2P Volunteer of the Year: Val Sutorius

TxP2P Advocate of the Year: Elizabeth Tucker

TxP2P Friend of the Year: United Healthcare

Val has been working with TxP2P from the beginning, was our first Board Chair, and learned how to run a nonprofit alongside the Co-Directors. Elizabeth is the “go to” person for anything on Medicaid Waivers and is always up to speed on legislative issues and willing to help TxP2P. And finally, United Healthcare has been a sponsor of our conference for the past 8 years and is always available to work with us on parents problems that relate to the health coverage with UHC. We thank them all for their contributions to TxP2P and to Texas families of children with disabilities, chronic illness and special health care needs.

Legislative Update

Linda Litzinger, TxP2P Staff

The Texas Legislature, the Health and Human Services Commission, and four newly appointed advisory committees have worked through the summer at an unprecedented pace to implement a legislative bill that covers health care and supported employment, Senate Bill 7. Our state agencies should be commended for accomplishing so much in one summer.

In January, the 84th Legislative Session will welcome a new Governor and Lt. Governor, and fur-

ther leadership changes in House and Senate committees. This is a great time for families to become involved in the legislative process.

In that vein, TxP2P is offering Legislative Advocacy training in the Capitol on September 26, 2014 and on October 30, 2014, during the school day. Additionally, I can escort families to visit with key legislators at a mutually convenient time. To register for trainings, visit our homepage, www.txp2p.org under Special Events and training or

for questions or to arrange legislative visits, contact Linda Litzinger at linda.litzinger@txp2p.org or at 512-922-3810 cell/text.



Will Makes a Move!

Rosemary Alexander, PhD, TxP2P Staff

When our son Will was 20, he moved from our family home to the home of his high school special education teacher; she was paid out of CLASS funds and through Will's SSI and food stamps card, but she really viewed Will as another member of her family. Her boys grew up seeing Will as a brother and her friends and extended family knew that Will would often be included in their joint activities. Will came to our house at least once a week, but over the years he came to see that household as family, too, and that house as home. He had two moms and two families.

It was a big step for all of us, but that step really enabled Will to grow into an adult through new expectations, new experiences, new learning and social opportunities, new relationships. He matured into a person who preferred adult activities and peer company, a person with unique needs and desires, someone ready to be as independent as possible. He lived with his second family for 12 years!

And then recently his "Mom #2" decided it was time to move on, now that her two sons were out of the house, and embark on new adventures. We agreed on a timetable for the changes and parted on very good terms. But Will's

father and I had a huge task ahead—where would Will live and with whom? We had three months before the agreed-on date to make the move.

We thought about buying a house and consulted with HOYO, the Home of Your Own organization that helps people with disabilities or their families to buy a house. However, the timing wasn't right—we didn't have the time needed to work with the HOYO folks to buy. We decided to rent, and we found a realtor who has a daughter with disabilities to help. We were especially eager to get Will out of a 2-story place into a 1-story, as Will's mobility had become an issue in the last year or so.

We decided on a price range for the rent (based on Will's monthly SSDI payment) and an area of town (about 5 miles maximum from our house), then we started looking. We spent a day or 2 a week for several weeks in the car with the realtor, driving around northwest Austin—we got to be pretty good friends with her! We looked at apartments, townhouses and houses. The first house we looked at was ideal—close to our home, not too big, not too small, one-story with no steps, open plan, light and clean, a sizable master bedroom, on a quiet street

near a major road (easy access for attendants who come and go). However, the owner was not open to our interest in renting, mainly because the people paying the rent weren't going to live there; he was also concerned that Will's disabilities would be hard on the house. He hadn't met Will, just knew he had a disability.

We continued the search but kept coming back to that first house. Then the realtor had the great idea of writing a letter to the house owner, including a photo of Will and telling about his disabilities, his need for a flat open plan, and our desire to find a place near our home. The owner turned into an ally! He switched from having doubts to "let's make this happen!"

The other huge concern was who would live with Will as his care provider. A friend had a part-time attendant for her son who wanted to move into Austin to be nearer her high school TA job, whose children had flown the coop, and who was ready for a move. We met and talked and soon decided that she would be great for the job; we arranged time for her to get to know Will and started talking about the details of his care and the home arrangement. We were offering her

continued on page 3

LISTSERV NOTICE: Yahoo Groups will no longer allow us to “add” people to our listservs - we can only invite you to join. Unfortunately, many of our invitations go into spam and you never see them. Another way to join the listservs is to send an email to the moderator and ask to subscribe. Contact Susan.Prior@txp2p.org if you want to join the any of the following: Advocacy, ADD/ADHD, Autism, Bipolar, Dad’s, Dyslexia, ECI, Homeschoolers, Medical Home, Medicaid Waiver, Mental Health, NICU, Rare & Undiagnosed, Spanish, Transition, or local area Listservs (Amarillo, Austin, Bryan/College Station, Coastal Bend/Corpus Christi, Dallas/Ft. Worth, El Paso, Houston, San Antonio, San Marcos, Rio Grande Valley, & Waco/Temple). If you want to moderate a local listserv for your area, we’d love to set up more local groups. Contact Laura at Laura@txp2p.org to discuss moderating one for us.

The TxP2P Newsletter is not copyrighted. Please feel free to use any of our articles in your newsletter, parent group meeting, or any other venue but remember to credit the author & TxP2P. If you would like an electronic copy, we can email it to you; please email the date of the newsletter & the article name to Susan.Prior@txp2p.org and we’ll email you the article.

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) and ask to receive the TxP2P Newsletter via email. If you leave a voice mail, please remember to give us your email address. Thanks!!

Will Makes a Move

Continued from page 2

the master bedroom and bath in a home in Austin, with rent paid plus some CLASS attendant hours, and in return, she would be Will's companion and care giver for mornings, evenings, and some weekends.

Meanwhile, we worked toward the move-in date. That involved:

- finding home furnishings (Will already had bedroom furniture and the new care provider provided kitchen stuff and her own bedroom furniture); I bought a used kitchen table and some living room furniture
- setting up utilities and cable
- working with the house owner to finish the renter contract and do the walk-through
- finding a truck and a teenager to move Will's clothes and furniture from house to house setting dates to move Will's stuff, meet the cable guy, and accept several deliveries

I had lists upon lists, and it took lots of time, planning and effort, but it all came together just in time for our date to make the move. And it has worked! Will lives with his new companion, still goes out on week days with other attendants to do a variety of activities, and has bonded with a new care-giver for his home life.

His companion's family comes and goes to visit, and we've used the extra bedroom for respite for another family's 20 year old. So far, so good!!

However, there is a big difference between his move-in 12 years ago and this one. Then he was still a youth at 20, just starting to live away from home, and it was a hard step for all of us. We thought in terms of Will's living in another person's home and his having another mom. Now that Will is 32, we are ready to make it Will's home, with a companion for care, but a home centered on his needs and desires. We are thinking in terms of the future, hoping to create a place and a system of care that can go on without us.

It has been a lot of work, but it's really been a joy to pop in for a visit or a meal, invite his network to meet at his place, set up a visit to his house for an old friend, and see him shine in his new place!

To learn more about funding through SSI, SSDI, CLASS and other Medicaid Waiver programs, go to www.txp2p.org, click on Pathways to Adulthood, and scroll down to Services and Supports. Also this DADS website provides information on Medicaid Waivers: [http://](http://www.dads.state.tx.us/providers/waiver_comparisons/)

www.dads.state.tx.us/providers/waiver_comparisons/ and click on Texas Long-Term Services and Support Waiver Programs.

To learn more about buying a house through HOYO, go to: <http://www.txhomeprograms.org/program/programdetail.php?id=261>

To learn more about planning a home for your child, go to www.txp2p.org, click on Pathways to Adulthood, and scroll down to Planning for Life after Graduation, then to Home.

You are also welcome to contact TxP2P to chat about setting up a home, but note that we have no direct services or easy answers! Call toll free: 866-896-6001 or Austin: 512-458-8600 or email cynda.green@txp2p.org or rosemary.alexander@txp2p.org.



Introducing TxP2P Mental Health and Rare & Undiagnosed Listservs

Laura J. Warren, TxP2P

We have been approached this month about starting 2 new listservs by parent volunteers willing to moderate them. So we have set up a listserv for mental health issues and for families whose children have rare or undiagnosed conditions. To subscribe to either of these, please email your email address to:

Rare & Undiagnosed Listserv:

txp2p-rare-undiagnosed-listserv-subscribe@yahoogroups.com

Mental Health Listserv:

txp2p-mental-health-listserv-subscribe@yahoogroups.com

Remember, we have added other listservs over the years and if you

are interested in joining any of these, please email your email address to:

Professional Listserv:

txp2p-professionals-subscribe@yahoogroups.com

ADD-ADHD Listserv:

txp2p-add-adhd-listserv-subscribe@yahoogroups.com

Advocacy Listserv:

txp2p-advocacy-listserv-subscribe@yahoogroups.com

Amarillo & Vicinity Listserv:

txp2p-amarillo_vicinity-subscribe@yahoogroups.com

Autism Spectrum Listserv:

txp2p_autism-subscribe@yahoogroups.com

Austin & Vicinity Listserv:

txp2p-austinvicinity-subscribe@yahoogroups.com

Bipolar Listserv:

txp2pbipolargroup-subscribe@yahoogroups.com

Bryan/College Station & Vicinity Listserv:

txp2p-bryancollegestationvicinity-subscribe@yahoogroups.com

Corpus Christi & Vicinity Listserv:

txp2p-corpuschristivicinity-subscribe@yahoogroups.com

Continued on page 4

Dads’ Group: txp2pdadsgroup-subscribe@yahoogroups.com

Dallas/Ft. Worth & Vicinity Listserv: txp2p-dallas-ftworthvicinity-subscribe@yahoogroups.com

Dyslexia Listserv: txp2p_dyslexia_listserv-subscribe@yahoogroups.com

ECI Listserv: txp2p_pride_eci_onlineforum-subscribe@yahoogroups.com

El Paso & Vicinity Listserv: txp2p-elpasolistserv-subscribe@yahoogroups.com

Espanol Listserv: txp2p-espanol-subscribe@yahoogroups.com

Houston & Vicinity Listserv: txp2p-houstonvicinitylistserv-subscribe@yahoogroups.com

Medicaid Waiver Listserv: txp2p_medicaid_waiver_listserv-subscribe@yahoogroups.com

Medical Home Listserv: txp2pmedicalhome-subscribe@yahoogroups.com

NICU (Neonatal Intensive Care Unit) Network Listserv: txp2p-nicunetwork-subscribe@yahoogroups.com

Rio Grande Valley & Vicinity Listserv: txp2p-riograndevalleylistserv-subscribe@yahoogroups.com

San Antonio & Vicinity Listserv: txp2p-sanantoniovicinitylistserv-subscribe@yahoogroups.com

San Marcos & Vicinity Listserv: sanmarcosvicinity-subscribe@yahoogroups.com

Special Home Schoolers Listserv: txp2pspecialhomeschoolers-subscribe@yahoogroups.com

Transition Listserv: txp2ptransitionlistserv-subscribe@yahoogroups.com

Waco/Temple & Vicinity Listserv: txp2p-wacotemplevicinity-subscribe@yahoogroups.com

Texas Parent Group Network Listserv: texasparentgroupnetwork-subscribe@yahoogroups.com

Congratulations to the Paying It Forward Award Winners

Jan DiMare, TxP2P Staff

This year at the TxP2P conference, we celebrated our 3rd Annual Paying It Forward Awards. We had great entries and lots of on-line voting. We even had international voting! The winner of the Laura J. Warren Paying It Forward Champion Friend Award went to Shannon Coffman. Shannon was nominated by her friend Rasha Kawar. Rasha and Shannon have been friends since high school. Rasha says that Shannon always saw her as a typical teenager, not as a person with a disability. Thanks to the friendship that has grown over the years, Shannon has inspired Rasha to do more than Rasha thought possible.



Congratulations Shannon for being that Champion Friend. The Sue Regimbal Paying It Forward Champion Professional Award goes to Angela Stephens, Director of *It’s a Sensory World*, nominated by Crystal Lopez. Angela has worked with Crystal’s daughter, Journey, and transformed her life. The two made a connection and Angela has given Journey the skills needed to thrive in her life and to have a voice to be heard by all. Angela sees no limitation in any child. All the children she works with catch Angela’s motivation and drive to be successful.

Congratulations Angela for being that Champion Professional.



Get ready for the **2015 Paying it Forward Awards**. Be thinking of that Parent or Professional who has helped you in your journey of raising your child. Call for nominations will go out in early January 2015. The winners and their nominators will win a free registration to our 2015 Texas Parent to Parent Conference. What a fantastic way to honor someone by paying it forward!



Emergencies can occur without warning. What would you do if basic services—water, gas, electricity or telephones—were cutoff for several days? Families can cope with emergencies by preparing in advance and working together as a team. For families of children with disabilities or special health care needs planning is critical. It means extra attention to details and needs that typical families may not have to worry about. Being prepared is your best protection. Here are some tips to help you prepare:

Create a Support Network: Create a support network by making a list of family, friends, co-workers, personal attendants, service providers and others who can be part of your emergency plan. Choose at least three people in each location where you spend time, such as home, school and your workplace.

Identify your Resources: Ask yourself what resources you rely on regularly and determine how power outages, lack of air conditioning, or refrigeration might affect your access and ability to use them.

Create a Communications Plan: Make sure you and members of your support network have a list of contact information for everyone in the network, along with names of your doctors and other service care providers. Make sure you have alternate ways to communicate if phones are not working.

Pack an Emergency Supply Kit: Families of children with disabilities must be prepared to manage their needs under all conditions including undesirable conditions. By gathering and storing supplies in advance, your family can more readily handle an evacuation or home confinement. To simplify the process, purchase and gather necessary items over a period of weeks or months each year. Every few months, recycle water, food and other perishable items from your kit.

Sample Supplies:

- Two week supply of all disposable medical supplies such as dressing materials, nasal cannulas, or suction catheters
- Two-week supply of all medications, prescription, non-prescription
- Generator or battery backup for all electrical medical equipment
- Copies of prescriptions for medical equipment, supplies, and medications
- Extra contact lenses and supplies or glasses
- Extra batteries for hearing aids, communication devices
- Special dietary foods and supplies
- Manual wheelchairs and other necessary equipment



Tips to Help You Support Your Children

1. **Don't get caught up in the "hype."** The potential for a disaster is often a great opportunity for media to increase their audience.
2. **Have a plan and know what you will do.** It is the unknown that frightens most people. Most children and youth are more frightened about what they think might happen than by reality. Planning and practicing makes the unknown easier for children.
3. **Talk on a level that your child can understand.** Children of all ages will know or sense that something is wrong. Infants and young children may not understand your words, but take the time to hold them and tell them how much you love them and that you will always

do your best to care for them. Singing and playing games they recognize can help calm them.

4. Keep routines and regular schedule.

5. Make sure children know what to do if you are not around. If your child is old enough to talk, they should be taught your name. Older children should be taught their address, phone number, and your cell phone number. Make sure your children have some identification on them even if they are with you such as an information card in their pocket on how to get a hold of you should you be separated.

6. Make your child's disability known. If your child has special health care needs, make sure they have medical alert identification. This is especially important if they have a need that may not be obvious (such as diabetes, a chronic health condition, or allergy). Teach your child to answer questions about their condition and treatment as soon as they are old enough. This will help ensure that others can care for them in your absence. Also, keep a health history information form on your child in their pocket and make copies to keep with you. (<http://www.medicalalert.org>)

7. Teach your children to recognize and accept help from emergency officials. Be sure your children can recognize emergency officials, such as police, Red Cross, firemen, and others. Help them understand that if they are alone they can go to these people for help. It is important that they learn to NOT be afraid and hide from emergency officials as this can make locating them if they are separated from you easier.



Miscellaneous Resources

Parent Companion, Grants for Families, Hiring Videos, & Mitochondrial Disease Registry

Parent Companion - New Website for Families of Children from Birth to 5-years-old

There's a new website for Texas parents and caregivers of children with diagnosed or suspected disabilities from birth through 5 years of age – Parent Companion. The website was funded through the Texas Education Agency and was a collaboration of Education Service Center Region 13 and Texas Parent to Parent. Check it out: <http://www.parentcompanion.org/>

Potential Grants for Families

www.astrazeneca-us.com/help-affording-your-medicines

offering free medicines to people who earn \$30,000 a year or less, or a family of four making up to



\$60,000 a year without insurance

www.blindcitizens.org/assistive-tech.htm

The Assistive Technology Fund (ATF) will provide funds to cover 50% of the retail price of adaptive devices or software.

www.wheeltowalk.com

helps children who experience difficulty obtaining funding from their insurance companies to obtain essential equipment or services that they needed to make their day to day lives just a little easier.

www.s4af.org

Sports 4 All Foundation has an Equipment Endowment Program that provides sporting equipment, gear and clothing to individuals with disabilities.

www.smallstepsinspeech.org

helps children with speech and/or language disorders take the steps needed to be better communicators.

www.act-today.org

fund effective treatments, assessments and needed life supports with grants from \$100-\$5,000. Applications with multiple children with ASD and households with income below \$100,000 are reviewed first. This list of potential grants for families came from the Kaufman Children's Center for Speech, Sensory-motor, & Social Connections at http://www.kidsspeech.com/index.php?option=com_content&view=article&id=812&Itemid=639

Videos to Help Parents or Self-Advocates (Employers) When Hiring Attendants

Texas Department of Aging and Disability Services has created a webpage and videos to assist people when hiring attendants for children or adults with disabilities. If you are in this process or know you will be again, you might take a look at the site and see if it is something that would be helpful to educate a potential attendant – the videos are of attendants talking about their job and the webpage has ways to use the videos in the hiring process and other interviewing suggestions: <http://www.dads.state.tx.us/providers/jobpreview/employers.html#>

Mitochondrial Disease

Community Registry Launches

The creation and launch of the Mitochondrial Disease Community Registry (MDCR) marks a significant milestone for those affected by mitochondrial disease. For the first time in the brief known history of mitochondrial disease, our community will be collecting and sharing data in a manner that will positively impact the development of treatments and cures. The UMDf is committed to long-term financial sponsorship, serving as the guardian of the data, and to overall coordination of the project.

So what is the MDCR, who should register and why is it important? The MDCR will collect patient-centric health data that will be utilized to develop treatments, identify new symptoms (leading to better diagnoses) and provide information to researchers that seek to study mitochondrial disease. The MDCR will also identify new patients in need of support from our community. Our goal is to identify and characterize every person affected by mitochondrial disease, no matter where they are located, living or deceased. Caregivers and family members of those affected, whether themselves affected or not, are also encouraged to register and contribute to the community. The link to the Registry is: <http://www.umdf.org/site/c.8qKOJ0MvF7LUG/b.9135169/k.D604/Registry.htm?PEERREF=emb>

Please let us know if you are successful in receiving assistance through these resources: Laura@txp2p.org or call 866-896-



Texas Children's
Health Plan



Texas Children's
Hospital

Thank you to our 2014
Corporate Sponsors!!



RICHARD P. SLAUGHTER
ASSOCIATES, INC.

Charting Your Course to Financial Security



Driscoll
HEALTH PLAN

A friend of the family



SUPERIOR
Health Plan

Sometimes rough is not that bad...

Rosalba Calleros, TxP2P Staff

Every summer, we try to plan something fun to do with family and friends. It could be a quick trip to the beach and camping under the stars or just visiting some places in town where my teenage son, Alan, and his toddler sister can have some fun together. This summer, our biggest plan was a trip to Galveston; however, this trip was not for fun.

About 3 years ago, Alan started having pain in his left hip. I knew he had subluxation, dislocation and dysplasia in both hips but it never caused any pain so surgery was not needed. We didn't know if his pain was muscle or bone related so we tried some procedures like physical, aqua and electro therapy, Botox and Phenol injections, oral and intrathecal Baclofen therapy (ITB), and the selective percutaneous myofascia lengthening procedure (SPML). I was really hoping that one of these could alleviate his pain but we ran out of options and everything was pointing to be bone related. In other words, Alan had to go through a very painful surgery to stop the pain he has been in for the last three years.

A few weeks before surgery, Alan's pain was getting worse and he was losing mobility day by day. He was not the same social and happy boy he usually is. He started losing his enthusiasm and he started asking to just let him stay in bed. I could feel his pain in my heart and what I was feeling was excruciating. I tried to avoid this surgery for the longest time but I knew we just had to get it done. So, we made arrangements and scheduled his femoral rotational osteotomy in Galveston.

As the surgery day was approaching, I was feeling so many mixed emotions: I was so worried and vulnerable... but at the same time, I was feeling hopeful and happy just by thinking that this surgery

would let my son finally get relief, be pain free and more comfortable. I understood I was not really afraid of surgery, per se, since it was not his first one and I knew it was far from being an extremely dangerous procedure. However, I was very afraid of his recovery. I couldn't stand the idea of putting my child through so much more pain than what he was already feeling.

So, Alan and I drove to Galveston the night before his surgery. We decided to have a "Mom & Son" date. We went to the movies and got his favorite milk shake. Even though we had a lovely night, his eyes were yelling at me, "It hurts, mama!" That night, I was glad we were closer to end his pain despite the painful recovery coming up.

The next morning I wore my "strong mom" look - even if I didn't want to. Surgery lasted 6 hours and we spent 5 days in the hospital away from home. Recovery was as I expected it: draining and extremely painful, even after taking pain killers.

The worst moment was one night when Alan told me, "I just want to sleep forever." For a moment, I doubted if I had made the right decision for my son. Those words hurt deep in my heart. Then, I realized that I tried all those different procedures just because I heard they have worked beautifully for other children but it was not my son's case. I knew that it was a well informed decision to the best of my knowledge. We saw 3 different surgeons and I also talked to a couple of moms that have had the same procedure with their children. I knew we had to do this.

Three weeks after surgery, everything started to improve. He was feeling better, we didn't have to use strong pain killers, and he started asking his favorite question: "What are we doing



today?" We were very fortunate to have family and friends sending him encouraging and healing messages. Some others came to visit and cheer him up. My parents were in charge of spoiling him for 6 weeks and all that played an important role to get him ready to go back to school for his sophomore year in high school.

Now, the summer of 2014 is in the past, I just feel extremely happy that he is pain free. I have no regrets for not having this surgery before, I have no regrets for trying other methods, and I have no regrets for having this painful surgery. This summer was rough but once again, he showed his strength and I can't be happier!

Alan looking great and recovering!



Texas Parent to Parent
3710 Cedar Street, Box 12
Austin, TX 78705-1450

Toll Free: 866-896-6001
Local: 512-458-8600
Fax: 512-451-3110
Website: www.txp2p.org
Email: txp2p.org

ADDRESS SERVICE REQUESTED

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.



Schedule of Events

15th Annual Chronic Illness & Disability Conference: Transition from Pediatric to Adult-based Care	Houston, Oct. 2-3, 2014	http://www.baylorcme.org/search/detail.cfm?cme=954
8th Annual TFX Fall Festival & Dance	Carrollton, Oct. 11, 2014	www.txfx.org
23rd Annual Texas Autism Conference	Corpus Christi, Nov. 6-7, 2014	www.txautism.esc2.net
Gulf Coast of Texas African American Family Support Conference	Houston, Nov. 7, 2014	www.gcaafsc.net/events



THANKS TO GLOBAL PRINTING SOLUTIONS FOR PRINTING THIS NEWSLETTER AT A REDUCED COST FOR TXP2P!

5114 Balcones Woods Dr., Ste. 309, Austin, TX 78759
512-794-8000, www.gpsaustin.com