



Linking families of children and adults with disabilities or special needs
1-888-727-2706

Program Summary

FY 2012-2013

July 1, 2012- June 30, 2013



Leiana Smith enjoying a hug with Grandpa

Program Description:

Parent to Parent of Pennsylvania's mission is to link families of children and adults with disabilities or special needs together for purposes of support and information. The staff are located in five regional offices and four home-based offices across the state. A new Structured Query Language (SQL) database was rolled out to the staff in August 2012 and currently holds 1,507 Peer Supporters (mentors). Our Peer Supporters are the lifeline of the program; they are the ones who have experienced the joys and challenges of raising a child with a disability or special need and are willing to share their experiences with others by being "matched" over the phone to a Caller for support and information. Our program can match for physical disabilities, developmental disabilities, special health care needs, behavioral/ mental health concerns, foster care or adoption, educational issues or any other additional concerns that the family may need support for. Additional services include linking families to support groups and if requested providing technical assistance, recruiting and training Peer Supporters and marketing our services through outreach events such as presentations, exhibits and media outlets.

Making Matches:

The primary service provided by Parent to Parent is that of linking families of individuals with disabilities or special needs. The match process includes the completion of an intake interview via phone to gather information relevant to the individual's condition, the family situation, and special considerations for making a match. Potential Peer Supporters are then identified through a database search process or when necessary via external sources, such as the Parent to Parent USA list serve, our umbrella organization. When a Peer Supporter is identified and agrees to support, the two families are linked. Support generally occurs via phone but occasionally in person as well. Matches are generally to be completed within 24-48 hours of the original request.

A follow up call is made to both Caller and Peer Supporter within one to two weeks of linking the families. If a match was unsuccessful or unsatisfactory for any reason as identified by the caller, another match is made. The Parent to Parent of Pennsylvania program has the capacity to "match" families through the lifetime of the child addressing the child/adult's condition or secondary conditions, surgeries ,sibling issues, related services such as physical or speech therapy, transition and school concerns, to name a few. Families may be linked with more than one Peer Supporter at a time. A Caller Outcome survey is completed over the phone by the Regional Coordinator when a match is complete. If after 3 follow up phone calls to the Caller we are unable to reach a Caller to determine the satisfaction of a match, a Caller Outcome Survey is sent via mail.

- **Program Goal for FY 2012-2013- increase the number of matches made from FY 2011-2012 (897) to 1,000 matches.**



Alex and Isabell Lee



Megan Patrick

- ♥ **Program Outcome for FY 2012-2013- Parent to Parent of Pennsylvania reached a historical milestone by helping to provide support to 1,131 families; the most matches ever made in the history of the 17 year old program. A 26.1% increase from FY 2011-2012.**

- **Program Goal for FY 2012-2013- increase the number of matches made in the Early Intervention population 0-5 from FY 2011-2012 (461) to 508 matches.**



Adam Yahner

- ♥ **Program Outcome for FY 2012-2013- Parent to Parent of Pennsylvania successfully completed and exceeded our goal by matching 603 families who receive Early Intervention Services. A 30.7% increase from FY 2011-2012.**

Developing Outreach for the purpose of inviting families into the Parent to Parent Network:

The primary marketing mechanisms for Parent to Parent are presentations to parent groups and professionals and exhibits at conferences and community fairs. Networking with other organizations occurs at state, regional and local levels to support opportunities for outreach. Printed materials include rack cards in English and Spanish, outreach packets, peer supporter packets, retractable banners and small display boards are used for public relation purposes.



- **Program Goal for FY 2012-2013-continue prior statewide outreach strategies from FY 2011-2012 to generate calls to the Parent to Parent of Pennsylvania program with a range of 313-336 outreach events completed.**

- ♥ ***Program Outcome for FY 2012-2013- Parent to Parent of Pennsylvania successfully completed and exceeded our average goal of 325 outreach events for a total of 425, a 30.8% increase from FY 2011-2011. Our total attendance for outreach was 9,548.***

Peer Supporter Recruitment and Training

- ***Program Goal for FY 2012-2013- continue to maintain an average of 233 New Peer Supporters recruited annually to the Parent to Parent of Pennsylvania program.***

My Gift Author unknown

As a supporting parent, my message is:

I am a stranger to you now, but let me walk with you for a while. Because I have been where you are, and where you are about to go. I have no answers. I offer instead my hand, my heart, my listening ear, my time, and my experience... So that one day you can turn to another and say:

I am a stranger to you now, but let me walk with you for a while. Because I have been where you are, and where you are about to go. I have no answers. I offer instead my hand, my heart, my listening ear, my time, and my experience... So that one day...

- ♥ ***Program Outcome for FY 2012-2013- Parent to Parent of Pennsylvania successfully completed and exceeded our average goal of recruiting 233 New Peer Supporters for a total of 274, a 15% increase from FY 2011-2012.***
- ♥ ***Peer Supporter Online training is available to new and seasoned Peer Supporters by accessing the training link at training.parenttoparent.org and entering your User Name and Password.***

Expanding the Parent to Parent of Pennsylvania Program:

Purpose: to create a very specific matching program that was identified by parents of children with disabilities or special needs who were receiving services at a hospital or agency. These new matching programs would utilize the proven matching structure of the Parent to Parent of Pennsylvania program. Since 2011, Parent to Parent of Pennsylvania has collaborated with five hospitals and one Early Intervention agency in the state to create the following Affiliate Matching Programs that we administer:

- ♥ **Penn State Hershey Children's Hospital NICU Parent Support Program-** at Penn State Hershey Children's Hospital –matches families who currently have a baby in the NICU with Parent Supporters, who are other families who previously have had a baby in the NICU at Penn State Hershey Children's Hospital. Launched October 31, 2011.
- ♥ **Pediatric Therapy Professionals (PTP) Family Connection-**matches Parent Representatives, who are families who previously used the Early Intervention services of Pediatric Therapy Professionals, Inc., with families new to the Early Intervention Services available through PTP. PTP serves the counties of Allegheny, Beaver, Butler, Lawrence and Mercer. Launched August 8, 2011.
- ♥ **Trisomy 21 Parent Peer Program-** at Children's Hospital of Philadelphia (CHOP) matches Parent Peers, who are families of children or adults with a diagnosis of Trisomy 21 (Down Syndrome) with other families of children or adults with Trisomy 21 for emotional support and information. Launched May 30, 2013.
- ♥ **DuBois Regional Medical Center NICU Parent Support Program-**Matches families who currently have a baby in the DRMC NICU with Parent Supporters, who are other families who previously had a baby in the NICU at DRMC. Mentor base recruited at the DRMC NICU Reunion on August 30, 2012. Launch date December 17, 2012.
- ♥ **Geisinger Medical Center NICU Parent Support Program** –matches families who currently have a baby in the NICU with Parent Supporters, who are other families who previously have had a baby in the NICU at Geisinger Medical Center. Launch date-TBD.
- ♥ **York Hospital NICU Parent Support Program-** Matches families who currently have a baby in the York NICU with Parent Supporters, who are other families who previously had a baby in the NICU at York Hospital. Mentor base will be recruited this October 5, 2013. Launch date-TBD
- ♥ **Hands & Voices Guide By Your Side Program-** sister program to Parent to Parent of PA. GBYS matches families of children 0-3 who are deaf or hard of hearing to a Parent Guide. Parent Guides are parents of a child who is deaf, hard of hearing or deaf blind. They bring their direct experience, specialized knowledge and personal compassion to their role while making the family's needs their primary focus. Parent Guides are available to talk to the family or meet face-to-face. Administered by the Pennsylvania Department of Health.

Currently the Trisomy 21 and Penn State Hershey NICU parent support program descriptions and forms can be accessed on the Parent to Parent of Pennsylvania

website at www.parenttoparent.org .Our goal is to eventually have all of our Affiliate program information located on our website.

Another Successful Match-

Aubrey Ginocchietti was desperate. She had four toddlers being just that...toddlers.

Aubrey and Michael Ginocchietti are the proud parents of Lorenzo, Luciano, Nina, and Solana. Aubrey had given birth two years prior to a set of triplets at twenty-nine (29) weeks gestation. After a complicated pregnancy, two month NICU stay, and medical complications, Aubrey and her husband felt ready for the challenge when the trio was discharged from the NICU. However, the Ginocchietti's were not prepared for what was about to come next. When the triplets were four months old, Aubrey and her husband discovered that they were expecting again.

Baby Solana was born when the triplets were just a year old and starting to become mobile. As the children grew, they became more active and the busy parents were having a hard time keeping up. Taking care of one two-year old is a tremendous challenge, but the Ginocchietti's had three two-year old ex-preemies to contend with as well as a baby not far behind her older siblings. Aubrey felt "stressed to the max" taking care of all of those toddlers without a break in sight. Additionally, Aubrey felt overwhelmed with the triplets' developmental and medical issues due to their prematurity. She often compared the trio to her friends' children of similar age and felt saddened and frustrated that Nina, Luciano, and Lorezno didn't seem to follow "normal" developmental patterns. She felt that none of her friends or family members truly understood her situation. She felt alone.

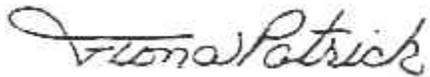
There was hope for Aubrey. During a routine visit, her children's Early Intervention team gave the Ginocchietti's a Parent to Parent of Pennsylvania rack card. Aubrey put the information aside until one day after a particularly difficult day with her crew. Aubrey said she "just started calling numbers on pamphlets" and as part of that outreach, Aubrey reached Jody Miller, Northeast Regional Coordinator. Jody knew who to match Aubrey with immediately! She knew that the Parent to Parent of Pennsylvania North Central Regional Coordinator, Nicole Golden, was the mother to 4 ½ year old quadruplets, born at twenty-six (26) weeks gestation. Jody knew Nicole's situation well. Jody knew that Nicole's children had various special needs. She knew Nicole often felt overwhelmed meeting Mark, Andrew, Tristan, and Lorelei's special health and developmental needs. She confirmed the match with Nicole and the two mothers of higher order multiples connected.

Aubrey was ecstatic. She said Nicole really made her feel like she wasn't crazy and was certainly not alone. Nicole even came to visit Aubrey and brought along another fellow quadruplet mother. After their visit, Aubrey told her friends and family "...today, I had lunch with two mothers of quadruplets and for the first time, I felt like I was in a country where other people spoke my language." Since that initial meeting, Aubrey has kept in contact with Nicole and they have continued to meet up in-person.

The two mothers provide each other with encouragement and camaraderie. Aubrey says "Nicole's words mean the world to us...they are what get us from one day to the next when she reminds us that things will get better."

Aubrey and her husband say that they have Parent to Parent of Pennsylvania to thank for bringing them much needed emotional support that could not have come from any other source. She says she will continue to recommend the valuable service that Parent to Parent of Pennsylvania provides to families with special circumstances- a friend, a comrade, a listening ear, and the satisfaction of knowing that someone has been in their shoes before!

Respectfully Submitted,

A handwritten signature in cursive script that reads "Fiona Patrick".

Program Director:

Fiona Patrick

6340 Flank Drive

Harrisburg, PA 17112

717-540-4722-phone

717-649-4861-cell

www.parenttoparent.org

fpatrick@pattan.net