Housekeeping

• This webinar is scheduled to last 1 hour, including Q&A.

• All dial-in participants will be muted to enable the speakers to present without interruption.

• The webinar is being recorded and will be sent via email with the slides, regional family-led organization reference guide and a brief evaluation survey after the live presentation.

• Questions can be submitted via the chat function at any time during this presentation. We will have a dedicated time to answer questions at the end of the presentation.
Agenda

• Introduction to the Family Center
• Parent to Parent USA Presentation
• Question & Answer
National Genetics Education and Family Support Center (Family Center)

Made up of:
- Genetic Alliance
- FAMILYVOICES®
- P2P USA

Funded by HRSA to:
- Help families develop skills to partner with professionals and improve systems of care
- Assist RGNs in partnering with families & family-led orgs
- Assist with outreach to diverse & medically underserved families
- Provide Education & Support
Family Center Regional Guides: Referral to Support and Partnering with Family-Led Organizations

REFERRAL TO SUPPORT AND PARTNERING WITH FAMILY-LED ORGANIZATIONS: A REFERENCE GUIDE

The National Genetics Education and Family Support Center (Genetics Education & Family Support Center) is a companion project to the Regional Genetics Networks (RGNs). RGNs link medically underserved populations to quality genetic services and provide resources to genetic service providers, Primary Care Physicians, public health officials, and families. In many cases though, linking isn’t enough. Individuals and families need direct support and assistance.

The Genetics Education & Family Support Center works to:

1. Assist the RGNs in their efforts to develop meaningful partnerships with families and family-led organizations and reach medically underserved and diverse families.
2. Provide emotional, informational, and navigational support for individuals and families who have, or are at-risk of having a genetic condition;
3. Provide education and resources on genetic conditions;
4. Link individuals and families to services and supports, especially those families in underserved areas
5. Help families develop skills to partner with professionals and improve systems of care

The following family-led organizations can help families navigate the system of care system and connect families to the information, resource, and support services they may need. In addition, family-led organizations can partner with RGNs and other families to help build capacity for family leadership and engagement to improve genetic educational materials, services, and programs.

| FAMILY-LED ORGANIZATIONS: MOUNTAIN STATES REGIONAL GENETICS NETWORK (MSRGN) |
|-----------------|-----------------|-----------------|
| **Texas**       | **Utah**        | **Wyoming**     |
| Texas Parent-to-Parent | Texas Parent-to-Parent | UPLIFT       |
| 512-458-8600 or 866-896-6000 | 512-458-8600 or 866-896-6001 | 800-692-3199 |
| Texas Parent-to-Parent | Texas Parent-to-Parent | UPLIFT       |
| Texas FCN     | Texas Parent-to-Parent | UPLIFT       |
| 512-864-9972 | 512-458-8600 or 866-896-6001 | 800-692-3199 |
| E-mail: [fcncfexas@gmail.com](mailto:fcncfexas@gmail.com) | [https://www.pgppb.org/services/family-tc/family-health-info](https://www.pgppb.org/services/family-tc/family-health-info) | [https://www.pgppb.org/services/family-tc/family-health-info](https://www.pgppb.org/services/family-tc/family-health-info) |
| There are 3 PTIs in Texas. Identify the PTI for your region TX at [http://conexsys.org/about-pm/find-your-pm/](http://conexsys.org/about-pm/find-your-pm/)
| PATH Project   | There are 3 PTIs in Texas. Identify the PTI for your region TX at [http://conexsys.org/about-pm/find-your-pm/](http://conexsys.org/about-pm/find-your-pm/) | PATH Project   |
| 403-896-6684 or 800-866-4716 | [http://conexsys.org/texas-pts/path-project/](http://conexsys.org/texas-pts/path-project/) | 915-259-8717 |
| NNN Project    | There are 3 PTIs in Texas. Identify the PTI for your region TX at [http://conexsys.org/about-pm/find-your-pm/](http://conexsys.org/about-pm/find-your-pm/) | 915-259-8717 |
| Utah Parent Center | Contact a neighboring state | UPLIFT       |
| Utah Parent Center | Contact a neighboring state | UPLIFT       |

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- **Texas Parent-to-Parent**
  - 512-458-8600 or 866-896-6000
  - [https://www.pgppb.org/services/family-tc/family-health-info](https://www.pgppb.org/services/family-tc/family-health-info)
- **Utah Parent Center**
  - 801-272-2051 or 800-468-1160
  - [http://conexsys.org/texas-pts/team-project/](http://conexsys.org/texas-pts/team-project/)
- **Wyoming**
  - 800-692-3199
  - [https://www.pgppb.org/services/family-tc/family-health-info](https://www.pgppb.org/services/family-tc/family-health-info)
Parent to Parent USA
Lily Brown, Co-Executive Director, P2P USA
Marsha Quinn, Co-Executive Director, P2P USA
Carmina Cirioli, Co-Executive Director, PATH
Parent to Parent/Family Voices of CT & Parent to Parent USA Board President
**The Four Stages of Adaptation**  
*by Dr. Nancy Miller*

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<th>Surviving</th>
<th>Searching</th>
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<td>• What you do to keep going when you are feeling completely overwhelmed</td>
<td>• A time of acting, of moving forward from your reactive stage of Surviving</td>
<td>• Gaining a greater sense of control over your daily life</td>
<td>• A necessary process in development</td>
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<td>• Coping and reacting</td>
<td>• The awakening of a sense of control</td>
<td>• A shift in balance, your definition of &quot;normal&quot; changes</td>
<td>• Small steps to independence throughout childhood</td>
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Where did we come from?

- **1971**- Greater Omaha Arc in Omaha, Nebraska to establish Pilot Parents of Nebraska, a program in which parents of children with disabilities could share information and emotional support with other parents through a one-to-one match.

- **1974**- Four more Parent to Parent programs launched in Nebraska, Iowa, Kansas, and Missouri

- **2003**- Parent to Parent of the United States (Parent to Parent USA) was created with funding from the Robert Wood Johnson Foundation to ensure that families nationwide whose children have special needs have access to Parent to Parent support.

- **2006** Parent to Parent USA was incorporated as a 501(c)(3).
Where did we come from?

Roadmap

Brief history

1971 Parent Fran Porter and social worker Shirley Dean petitioned Omaha ARC to establish Pilot Parents of Nebraska

1974 OK, IA, KS, MO, and NE Member Organizations Began

1976 First 5 Parent Training and Information Centers funded

1992 Family Voices established as an independent voice for families of children and youth with special health care needs

1992 MA and NV Member Organizations Began

1996 OK, NJ and PA Member Organizations Began

1997 CO Member Organization Began

1998 MA and NO Member Organization Began

2002 Parent’s Parent Handbook published; Authors: Santelli, Poyadue, Young

2003 Leadership team established through RWJF grant to create P2PUSA; website designed, mission/goals developed

2004 22nd ANA Convention in Dallas; P2PUSA experienced growth

2005 FDA approves DE contingent upon additional evaluation

2006 Funding approved for Family-to-Family Health Information Centers (F2FHICs)

2007 50 states have P2P

2008 P2P USA Logo Trademark awarded

2009 AMCHP goal: develop partnerships; International conference on Patient- and family-centered Care

2009 Family-to-Family Health Information Centers established in all 50 states

2010 MN Member Organization Began

2011 Opened office in Washington, DC; hired first ED

2012 AMCHP conference in DC; goal: expand awareness of P2P USA, hosted session and Directors meeting

2012 CA and OR Member Organizations Began

2013 Accomplishments: NASDUP Community of Practice Grant; new Community Partners Alliance memberships

2014 CA, OR Member Organization Began

2014 Quality Trust / Supported Decision-making for Guardianship grant; Sibling Leadership Network’s Resource and Training Center subcontract

2017 MD Member Organization Began

2018 DC Member Organization Began

2018 P2FHICs expanded to include centers in US territories and 3 Native American Communities (American Indian and Alaska Native families)

2018 Education Act P.L. 94-142 guarantees a free, appropriate public education for all children with disabilities; ages 5-21

1975 PA Member Organization Began

1979 AZ Member Organization Began

1980 WA and OR Member Organizations Began

1981 Medicaid Home- and Community-Based Waivers signed into law by president Ronald Reagan, following advocacy by Iowa parent Julie Beckert, on behalf of her daughter Katie

1982 KY Member Organization Began

1987 ND and WI Member Organizations Began

1988 VT Member Organization Began

1989 NH and NC Member Organizations Began

1990 IN and SC Member Organizations Began

1991 P2P Efficacy Study, NIDRR-funded Participation Action Research: Results; Evidence-based Practices

1993 P2P, Efficacy Study, NIDRR-funded Participation Action Research: Results; Evidence-based Practices

2000 Parent’s Parent Handbook published; Authors: Santelli, Poyadue, Young

2001 TX Member Organization Began

2003 Leadership team established through RWJF grant to create P2PUSA; website designed, mission/goals developed

2005 QA/QP and DE Member Organizations Began

2005 7,570 families matched nationally

2007 44 states have P2P

2007 Copyright to P2P Handbook transferred to P2P USA

2008 P2P USA Logo Trademark awarded

2008 MI Member Organization Began

2009 AMCHP goal: develop partnerships; International conference on Patient- and family-centered Care

2009 Family-to-Family Health Information Centers established in all 50 states

2010 MN Member Organization Began

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Our mission and vision

**Mission:** Our mission is to support a national network of Parent to Parent programs to ensure access to quality emotional support for families of individuals with disabilities and/or special health care needs.

**Vision:** Parent to Parent USA will support a network of viable, sustainable, fully-functioning and effective Parent to Parent programs in all 50 states through hands-on support, training and technical assistance, and high quality tools and resources. Our network’s parent leadership and engaged membership will serve as strong advocates, provide robust mentoring opportunities, and develop the working partnerships with funders, service providers, and others needed to sustain and grow the program nationwide.
Our Values

- Each family’s journey has value and can offer hope and inspiration to others.
- Peer support fosters mutual growth and resilience in families and among programs.
- Evidence-based practices ensure consistency and quality throughout the network.
- Leadership, integrity, and partnership build capacity and sustainability.
Support Parent Training Modules

Part One: About Parent to Parent

Part Two: LEARNING
- Increasing Knowledge to Support Others

Part Three: FEELING
- Understanding and Coping with Emotions

Part Four: LISTENING
- Communicating in a Support Role

Part Five: CARING
- Encouraging Parents to Care for Themselves
Support Parent Training

Formally Trained Volunteers
In person/online
5 hour typically
10-12 people
Making the Match

Seeing the Support Parent as a reliable supporter depends on three components:

- Similarities, or a sense of sameness, between the parents and their children with special needs and their situations
- Flexible availability of support.
- Support that flows both ways.

Matches can be made based on many different factors:

- Diagnosis, age of child, geography, cultural/ethnicity, language, etc.
Network for Matching

- Each organization maintains a roster and/or database of volunteer support parents that are available for one-to-one matches with referred parents.

- All alliance members have access to national listserv platform:
  - Matching Group: allows our organization’s Coordinators access to a national network of Support Parents where rare genetic and diagnosis matches can be made.
P2P Best Practice Timeline for Parent Support Match

- Contact the referred parent within 24 to 48 hours
- Connect referred parent to supporting parent and/or requested resource(s)
- Follow up with the parent and supporting parent within 1 week
- A Total of 4 Contacts within the first 8 weeks of referral
- x4 contacts
- Evaluation call 8 weeks after match
What is our impact?

“Mentors make a huge difference in giving me the confidence to care for my child.”

Source: P2P USA 2018 Annual Member Survey
How do we execute?

36 Alliance Members

ensuring access to quality emotional support for families of individuals with disabilities or special healthcare needs

2 Community Members

Source: P2P USA 2018 Annual Member Survey

96% of P2P staff are parents of children or youth with disabilities or special healthcare needs

19 Languages spoken by P2P staff

Source: P2P USA 2018 Annual Member Survey
Camaraderie- **noun**

mutual trust and friendship among people who spend a lot of time together.

**synonyms:**

- friendship · comradeship · fellowship · good fellowship · companionship · brotherliness · brotherhood · sisterhood · closeness · affinity · togetherness · solidarity · mutual support · sociability · team spirit · comradery · esprit de corps
“Tennessee Parent to Parent has given me the opportunity to take my NICU experience with 25 week twins and use it to pour support and encouragement into other parents walking through the same journey”.

The Scott Family
“P2P connected me with a valuable resource who provided relatable advice and uplifting support while my baby was in the NICU”.

Olivia Gianeselli, parent of Stuart Anne Gianeselli - Tennessee
“Parent to Parent introduced my husband and I to our first “Down syndrome family” while I was pregnant with our baby who had a prenatal diagnosis of Ds. Meeting the McMahan Family showed us that even though life was going to look a little different than we planned, everything was going to be OK. Spending hours playing and talking with the family was just what we needed!”

Melanie Harrington, WA
‘Parent to Parent was the first time I said “my daughter has Down syndrome” to a stranger. It was where I could be a first time mom, and not feel like an outsider. It has been the connection to amazing and cherished friends. It means everything.”

Sheila McMahan, WA
Takeaways/Collaboration Opportunities

- Disseminate materials on genetic support and family engagement to our Members and families
- Connect with parents who receive genetic services for input
- Share P2P resource to families who receive genetic services for ongoing support

- To connect with Parent to Parent USA, please contact us at: memberinfo@p2pusa.org
Thank you!

Natasha Bonhomme
nbonhomme@geneticalliance.org
www.expectinghealth.org

Marsha Quinn
mquinn@p2pusa.org
www.p2pusa.org

Lily Brown
abrown@p2pusa.org
www.p2pusa.org

Carmina Cirioli
ccirioli@pathct.org
www.pathct.org