



*Building  
Collaborations  
to Improve Care  
for  
Children & Youth  
with  
Special Health  
Care Needs*



# The Power of Partnerships

## Family Leadership Meeting

May 18-21, 2014

CONFERENCE PROGRAM BOOK

FAMILY  VOICES<sup>®</sup>

McDermott  
Will & Emery

The McDermott Building  
500 North Capitol Street, NW  
Washington, DC 20001





## We are honored to support your work.

McDermott Will & Emery proudly sponsors the Family Voices Leadership Meeting. We share their ongoing commitment to provide every child and youth with special needs family-centered health care, information and advocacy.

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**Welcome to the 2014 Family Voices Family Leadership Meeting: The Power of Partnerships!**

Family Voices is delighted to bring together family leaders, colleagues, and partners from across the country for three days of interactive sessions on contemporary issues that impact children and youth with special health care needs and their families. We extend a warm welcome to newcomers and seasoned leaders. We hope you will reach out to meet someone you don't already know, learn from each other, and explore our shared goals, challenges, and vision.

Family Voices expresses our appreciation to the McDermott Will & Emery Law Firm for their generosity in donating their stunning conference facilities. As you take in the magnificent view of our nation's Capitol, we invite you to reflect upon how you will take what you learn back home to make a difference in the lives of children and youth with special health care needs and their families. We are grateful to our corporate sponsors and those who have taken out ads to support this meeting. The Maternal and Child Health Bureau (MCHB) has in large part made this program possible through their funding support of the National Center for Family/Professional Partnerships and Family to Family Health Centers to participate in this meeting. Family Voices applauds MCHB for their historic commitment to family leadership.

The program is designed to provide the most current information in health care and wellness for children and youth with special health care needs; networking opportunities to meet colleagues, federal officials, and national partners; and to make your voice heard on Capitol Hill on behalf of families of children and youth with special health care needs. The program culminates on the third day with the National Family Voices Board of Directors and Staff strategic planning meeting. The information gathered throughout the meetings will be used to assist the board to make informed decisions regarding the future of Family Voices.

Thank you for your contributions in helping us design the program – completing the environmental scan, the surveys from which the agenda was designed, contributing information about your work, and volunteering your expertise to present and facilitate sessions.

In these challenging times as we face threats to funding, it is more important than ever for family leaders to share effective strategies to support families. We celebrate your leadership, family and professional partnerships and the impact our collaborative work has in creating health care systems that are responsive to families throughout the country and improve the lives of children and youth with special health care needs and their families.

Enjoy the meeting!



*Molly Cole*  
Molly Cole  
President



*Cristine Marchand*  
Cristine Marchand  
Executive Director



*Lynda Honberg*  
Lynda Honberg  
Director of Strategic Partnerships

## CONFERENCE SPONSORS

FamilyVoices gratefully acknowledges the support of the Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs for providing funding for this meeting through cooperative agreement #U40MC00149, the National Center for Family/Professional Partnerships.

FamilyVoices wishes to express our sincere gratitude to the law firm of McDermott Will & Emery LLP for their generosity in donating their beautiful facilities for this meeting.

This meeting would not have been possible without the generous support of our sponsors:

- The Child & Adolescent Health Measurement Initiative
- Children's Hospital Association
- Lake Research Partners
- National Center for Children's Vision & Eye Health at Prevent Blindness
- Lucile Packard Foundation for Children's Health
- Hawai'i MCH LEND Program
- Hawai'i Pediatric Association Research and Education Foundation
- Association of Maternal & Child Health Programs
- Community Catalyst
- APEX
- FamilyVoices Board of Directors
- Catalyst Center
- DeLong Lithographics
- Statewide Parent Advocacy Network of New Jersey
- Sputnik Moment
- National Center for Medical Home Implementation
- National Center for Hearing Assessment and Management
- National Institute for Children's Health Quality
- FamilyVoices Staff
- FamilyVoices of Indiana
- New Hampshire FamilyVoices
- Youth Transitions Collaborative
- Paul Newacheck



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Behind **Speak Now for Kids** are America's children's hospitals in partnership with the Children's Hospital Association. Together we advocate on a continual basis to help policy makers at all levels of government — local, state and federal — make the right decisions for children's health.

**Speak Now for Kids** is a national online network of parents, grandparents, teachers, nurses, doctors, hospital workers, teens — **people like you** who care about how kids' health care affects our future.

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- Join the network and become a champion
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- Take action by writing your members of Congress
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For more information visit [www.speaknowforkids.org](http://www.speaknowforkids.org).

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The Child & Adolescent Health Measurement Initiative  
Promoting early and lifelong health using family-centered data and tools

The CAHMI is honored  
to partner with

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to promote the early and lifelong health  
of children, youth, and families.



Find us on the web at:

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[www.YourChildsHealthcare.org](http://www.YourChildsHealthcare.org)

Follow us on:

Facebook: Data Resource Center  
for Child & Adolescent Health

Twitter: @ChildHealthData

## SCHEDULE AT A GLANCE

### Sunday, May 18: Phoenix Park Hotel, Powerscourt Room

4:30pm - 7:00pm Registration  
 5:00pm - 7:30pm Reception

### Monday, May 19: McDermott Building, The Capitol Room

8:00am - 4:00pm Registration  
 8:30am - 9:00am Continental Breakfast  
 9:00am - 9:15am Welcome  
 9:15am - 10:30am Plenary  
 10:30am - 10:45am Break  
 10:45am - Noon Breakout Sessions  
 Noon - 1:20pm Lunch - Listening - Learning - Leading  
 1:20pm - 1:30pm Break  
 1:30pm - 3:30pm Breakout Sessions  
 3:30pm - 3:45pm Break  
 3:45pm - 5:00pm Breakout Sessions

### Monday Evening, May 19:

#### Rayburn House Office Building, Room B340

6:00pm - 8:00pm From the Heart: Honoring Family Voices' Legislative Champions Reception

### Tuesday, May 20: McDermott Building, The Capitol Room

8:00am - 5:00pm Registration  
 8:00am - 8:50am Continental Breakfast - Round Tables  
 8:50am - 9:00am Break  
 9:00am - 10:30am Plenary  
 10:30am - 10:45am Break  
 10:45am - Noon Environmental Scan: Presentation and Reactor Panel  
 Noon - 1:30pm Regional Breakouts/Working Lunch  
 1:30pm - 1:50pm The Inside Scoop  
 1:50pm - 2:00pm Concluding Remarks  
 2:00pm - 2:30pm Preparation for 'Family Voices Day on the Hill'

### Wednesday, May 21: McDermott Building, The Capitol Room

8:00am - 2:00pm Board/Staff Strategic Planning Meeting (Closed)  
 2:00pm - 2:30pm Board of Directors Meeting (Closed)

## SCHEDULE

### Sunday, May 18: Welcome Reception

Powerscourt Room (2nd floor)  
 Phoenix Park Hotel  
 520 North Capitol St NW, Washington, DC 20001

4:30pm - 7:00pm  
**REGISTRATION OPEN**

5:00pm - 7:30pm  
**RECEPTION**

All are welcome to join us for this opening reception of the 2014 Family Voices Leadership Meeting. Molly Cole, President, Family Voices Board of Directors, will provide opening remarks. Participants are welcome to network with other attendees while light refreshments are served.

Evening  
**DINNER ON YOUR OWN**

Meet in the lobby if you wish to have dinner with others from your region.



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[www.thenytc.org](http://www.thenytc.org)

# SCHEDULE

## Monday, May 19: Leadership Meeting

The Capitol Room (9th floor)  
 McDermott Building  
 500 North Capitol Street, NW, Washington, DC 20001

➤ 8:00am – 4:00pm  
**REGISTRATION OPEN**

➤ 8:30am - 9:00am  
**CONTINENTAL BREAKFAST**

➤ 9:00am - 9:15am  
**WELCOME**  
 Molly Cole, President, Family Voices Board of Directors  
 Leolinda Parlin, Treasurer, Family Voices Board of Directors  
 Nora Wells, Co-Director, Family Voices National Center for Family/Professional Partnerships



➤ 9:15am - 10:30am  
**PLENARY: PROMOTING HEALTH AND WELLNESS THROUGH THE ACA**  
 Children and youth with special health care needs are particularly vulnerable to preventable conditions, such as obesity, mental health conditions, and secondary health issues and frequently don't get the preventive services or wellness education that could benefit them physically and emotionally. This panel will discuss the range of health and wellness promotion activities funded or otherwise encouraged by the ACA; how the law's incentives will shape future health polices and activities at the state, local, and provider levels; and opportunities for families and family-led organizations to inform these policies and collaborate in these activities.

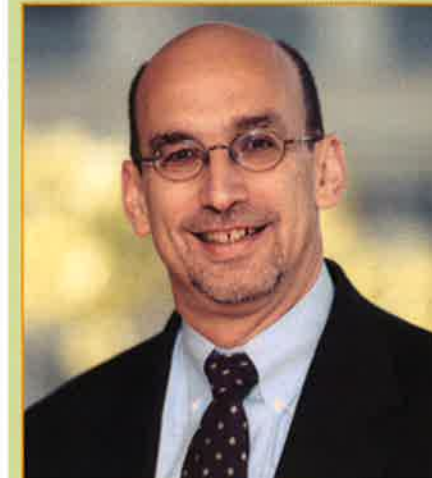
**Moderator:**  
 Juno Duenas, Executive Director, Family Voices of California, Support for Families of Children with Disabilities

**Speakers:**  
 Jeff Levi, PhD, Executive Director, Trust for America's Health  
 Judith Shaw, Ed.D., M.P.H., R.N., University of Vermont, Research Associate Professor, Department of Pediatrics  
 Joy Johnson Wilson, Health Policy Director and Senior Federal Affairs Counsel, National Conference of State Legislatures

➤ 10:30am - 10:45am  
**BREAK**

### MONDAY PLENARY SPEAKER BIOS

**Jeff Levi**



Jeff Levi, PhD, is Executive Director of the Trust for America's Health, where he leads the organization's advocacy efforts on behalf of a modernized public health system. He oversees TFAH's work on a range of public health policy issues, including implementation of the public health provisions of the Affordable Care Act and annual reports assessing the nation's public health preparedness, investment in public health infrastructure, and response to chronic diseases such as obesity. In January 2011, President Obama appointed Dr. Levi to serve as a member of the Advisory Group on Prevention, Health Promotion, and Integrative and Public Health. In April 2011, Surgeon General Benjamin appointed him chair of the Advisory Group. Dr. Levi is also Professor of Health Policy George Washington University's School of Public Health, where his research has focused on HIV/AIDS, Medicaid, and integrating public health with the healthcare delivery system. He has also served as an associate editor of the American Journal of Public Health, Deputy Director of the White House Office of National AIDS Policy.

**Judith Shaw**



Dr. Judith Shaw has been Executive Director of the Vermont Child Health Improvement Program (VCHIP) since its inception in 1999. In addition, she is Principal Investigator for several federally-funded projects designed to improve delivery of health care to children and holds the position of Associate Professor of Pediatrics and Nursing at the University of Vermont. Dr. Shaw earned her nursing degree from the Children's Hospital School of Nursing in Boston, bachelor's degree from Yale University, Master of Public Health degree from Boston University, and doctorate in education from the University of Vermont. Nationally, Dr. Shaw is co-editor of the 2007 American Academy of Pediatrics (AAP) publication of Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, Third Edition. In 2007 she received the Director's Award from the Health Resources and Services Administration's (HRSA) Maternal Child Health Bureau (MCHB). She was a DHHS Secretary's Primary Care Health Policy Fellow in 2002, on the Board of Directors of the Academic Pediatric Association from 1999-2002 and was reelected to the board in 2009-2012 and 2014-2021.

**Joy Johnson Wilson**



Ms. Wilson is the Director of Health and Human Services Policy and Senior Federal Affairs Counsel at the National Conference of State Legislatures (NCSL). NCSL represents the legislatures of the 50 states, its commonwealths, territories and the District of Columbia. As Senior Federal Affairs Counsel, she assists with overall government relations and public affairs activities in the NCSL Washington Office. As Director of Health and Human Services Policy, she designs and implements the lobbying strategy for the conference on health and human services issues. She also staffs the NCSL Task Force on Federal Health Reform Implementation. Ms. Wilson has been with NCSL since 1978. She took a leave of absence in 1989 to serve on the staff of the U.S. Bipartisan Commission on Comprehensive Health Care, better known as the "Pepper Commission." On the Pepper Commission staff, she was the liaison to groups representing state and local elected officials, organized field hearings and worked on issues related to the impact of health care reform on small business. She served as a non-voting member of Medicaid Commission established by Secretary Mike Leavitt of the U.S. Department of Health and Human Services during his tenure as Secretary. Ms. Wilson is a member of the National Academy of Social Insurance, a nonprofit, nonpartisan organization made up of the nation's leading experts on social insurance.

➤ 10:45am - Noon

**BREAKOUT SESSIONS (Choose one)**

➤ **HEALTH LITERACY & HELPING FAMILIES NAVIGATE HEALTH INSURANCE**

In this changing health insurance climate, families, particularly underserved families from diverse populations, do not always have adequate information or understand how to access health insurance. This workshop will provide an overview and requirements for health literacy within the context of cultural and linguistic competence. It will be followed by presentations from family organizations that serve as ACA navigators on strategies and approaches to making health insurance information more accessible to diverse populations and building the “health insurance literacy” of underserved families.

**Speakers:**

Tawara Goode, Assistant Professor & Director, National Center for Cultural Competence, Georgetown University Center for Child & Human Development  
 Wendy Jones, Director, Children & Youth with Special Healthcare Needs Project, National Center for Cultural Competence, Georgetown University Center for Child & Human Development  
 Doreen Hodges, Executive Director, Family Voices of the District of Columbia  
 Sitara Nayak, Director of Support Services, Parent to Parent of Georgia

➤ **MEASURING FAMILY ENGAGEMENT: RE-ENVISIONING MCH 3.0**

MCH is re-envisioning their guidance for State Title V programs including how they accomplish and measure family engagement/partnership with the diverse families that they serve. This session will provide information on measuring and reporting on partnership with families within Title V programs, changes to the National Survey of Children’s Health on family satisfaction as they relate to this measurement, and information on the Family Voices Family-Centered Care Assessment (FCCA) Tool as a vehicle for measuring family-centered care between a family and a provider. Approaches and opportunities for how family leaders can participate in measurement at the national and state level will be discussed.

**Speakers:**

Kathleen Watters, MA, Public Health Analyst, Division of State and Community Health, MCHB  
 Nora Wells, Co-Director, Family Voices National Center for Family/Professional Partnerships  
 Susan Colburn, State Parent Consultant at Children’s Rehabilitation Service in Alabama and Co-Director, Family Voices of Alabama, Inc.  
 Deepa Srinivasavaradan, Family Resource Specialist, Statewide Parent Advocacy Network of New Jersey

➤ **DEVELOPING PARTNERSHIPS TO ADVANCE HEALTH CARE FINANCING FOR CHILDREN**

While the ACA includes important protections for CYSHCN, strategies to close benefit gaps and pay for additional services are still needed. Medicaid buy-in programs can help reduce problems of inadequate insurance. Section 2703, the Medicaid Health Home provision of the ACA, gives states an opportunity to create a state plan amendment that provides a mechanism for reimbursing services often not covered by primary insurance. The Catalyst Center will provide content expertise about these two mechanisms for improving financing of care and coverage for CYSHCN. Family leaders will provide examples of partnerships that helped to implement these strategies in their states.

**Speakers:**

Meg Comeau, MHA, Co-Principal Investigator, The Catalyst Center, Boston University School of Public Health  
 Laura Warren, Executive Director, Texas Parent to Parent  
 Cathy Hickey, M.ED, Project Coordinator, Massachusetts Family Voices at the Federation for Children with Special Needs

➤ Noon - 1:20pm

**LUNCH - LISTENING - LEARNING - LEADING**

**Introductions:**

Lynda Honberg, Director of Strategic Partnerships, Family Voices

**Welcome from NCFPP Project Officer:**

Bonnie Strickland, PhD, Director, Division of Services for Children with Special Health Needs, HRSA/MCHB  
 LaQuanta Smalley, MPH, Program Officer, Director of Family/Professional Partnerships, Division of Services for Children with Special Health Needs, HRSA/MCHB

➤ **Polly Arango Mentoring Initiative:**

Cristine Marchand, Executive Director, Family Voices

➤ **New Initiatives:**

Diana Autin, National Field Co-Coordinator, Family Voices  
 Mary Jo Paladino, National Field Co-Coordinator, Family Voices

➤ **Concluding Remarks:**

Beverly Baker, Co-Director, Family Voices National Center for Family/Professional Partnership

➤ 1:20pm - 1:30pm

**BREAK**



**COMMUNITY CATALYST**

*Because we all should have a say  
in decisions that affect our health*

<http://www.communitycatalyst.org/>

➤ 1:30pm - 3:30pm

**BREAKOUT SESSIONS (Choose one)**

➤ **TIPS & TOOLS TO SUSTAIN THE WORK OF FAMILY ORGANIZATIONS: "SHOW ME THE MONEY!"**

Family organizations frequently struggle with too much work and not enough funds! This workshop will provide tips and tools for securing funds needed to do the work of family organizations, including fee for service, special events, and grant funding that is "outside of the box." Participants will be encouraged to share ideas from their own successful fundraising.

**Speakers:**

Diana Autin, Executive Co-Director, Statewide Parent Advocacy Network of New Jersey  
Heather Pike, Administrative Director, Oklahoma Family Network

➤ **PARTNERING WITH NON-TRADITIONAL PARTNERS TO REACH AND SERVE DIVERSE FAMILIES**

Family organizations recognize that reaching the families who most need support is often the biggest hurdle to providing support services. This session will provide resources, information and skills that will help you build partnerships with non-traditional partners in order to reach those families. Join us for this active panel presentation from four states who have partnered with organizations that do not typically focus on CYSHCN, such as community health centers, child welfare agencies, childcare organizations, and others.

**Moderator:**

Jackie Richards, Executive Director, Family Connection of South Carolina

**Speakers:**

Todd Rundle, Program Manager for Family Services, West Virginia Family-to-Family Health Information Center  
Nina Baker, Health Information Coordinator, PTI Nebraska  
Jane St. John, Community Inclusion Specialist, Missouri Family-to-Family, UMKC-Institute for Human Development  
Marilyn Ruiz, Project Director, Family Network on Disabilities, Florida

➤ **CREATING SYSTEMS CHANGE AND POLICY ADVOCACY**

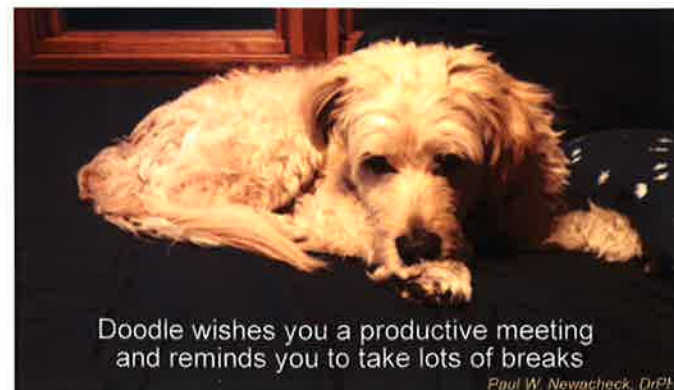
This session will focus on how family leaders can promote key partnerships and coalitions in their states to build effective policies for families of CYSHCN. Examples discussed will include a statewide coalition of multiple stakeholders with specific examples of accomplishments and strategies, a new national consensus document that provides guidance and highlights tools for change, and a campaign on systems improvement being undertaken by a national provider association.

**Moderator:**

Lynda Honberg, Director of Strategic Partnerships, Family Voices

**Speakers:**

Josie Thomas, Executive Director, Parents Place of Maryland  
Aimee Osman, Director of Policy Analysis, Children's Hospital Association  
Ed Schor, Senior Vice President, Programs and Partnerships, Lucile Packard Foundation



➤ 3:30pm - 3:45pm

**BREAK**

➤ 3:45pm - 5:00pm

**BREAKOUT SESSIONS (Choose one)**

➤ **F2F DATA: TRACKING IMPACT - MAKING AN IMPACT**

This workshop will provide information sharing on two key aspects of F2F data: impact data collection and potential uses of the data collected. F2F leaders will share their tips and strategies to successfully obtain impact data, including the use of surveys. This workshop will provide an opportunity to discuss ideas for potential uses of data within states and in other ways, and additional data tracked, such as data on ACA. MCHB Project Officer will provide perspectives from the federal level.

**Moderator:**

Nora Wells, Co-Director, Family Voices National Center for Family/Professional Partnerships

**Speakers:**

Martha Jean Madison, Co-Director, New Hampshire Family Voices  
Lisa Maynes, M.Ed., Associate Director of Family Support, Vermont Family Network  
Dana Yarbrough, Director, Center for Family Involvement, Virginia  
LaQuanta Smalley, MPH, Project Officer, Division of Services for Children with Special Health Needs  
Peggy Curran, Data Coordinator, Family Voices

➤ **HEALTH AND WELLNESS PROMOTION FOR FAMILIES: FAMILY WISDOM AND BEST PRACTICES**

Health and wellness (H&W) is a universal aim across all cultures. It is as important for CYSHCN as it is for the general population. IMPACT's family-led focus groups demonstrated enthusiasm and thirst for such information. This workshop will provide insights from states on health and wellness in their homes and communities. Sharing information provides a powerful platform for states to build H&W promotion into their programs and align with future funding possibilities.

**Speakers:**

Leslie Carroll, Director, Project IMPACT, Family Voices  
Mercedes Rosa, Director, NJ Family to Family Health Information Center, Director Innovative Evidence-Based Practices Project, Statewide Parent Advocacy Network of New Jersey  
Marlyn Wells, Program Coordinator, North Carolina Family Voices, Exceptional Children's Assistance Center  
Melissa Vickers, IMPACT Project Coordinator, Family Voices



➤ **REACHING FAMILIES WHERE THEY ARE: SOCIAL MEDIA 101**

Families and the professionals who serve them are seeking information via a wide variety of social media. Join us for an overview of platforms and how to use them to support your efforts. This session will help you plan a next step to start, expand or fine tune your social media efforts.

**Speakers:**

Rylin Rodgers, Director, Family Voices of Indiana  
Jessica Adair, Digital Strategy Manager, Young Invincibles



## SCHEDULE

### Monday Evening, May 19, 6:00-8:00pm From the Heart - Honoring Family Voices Legislative Champions Reception

Rayburn House Office Building, Room B340  
Washington, DC 20510

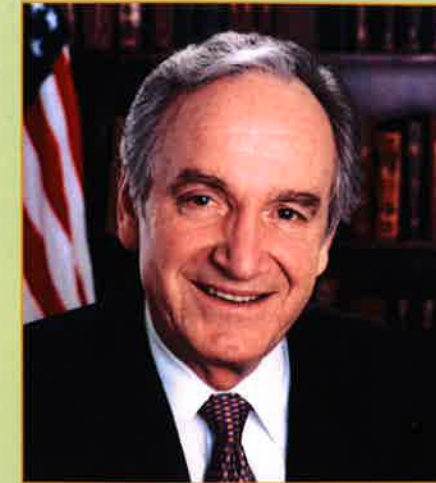
Please join us in honoring Congressional Champions who keep families at the center of children's health care. These champions have led the way to ensure families receive assistance, support and information to make informed decisions for quality health care for their children.

Enjoy light refreshments while learning more about the work of these leaders who have made a difference to families of children and youth with special health care needs. Meet legislative staff and share your knowledge of the successes and challenges experienced by families in your state.

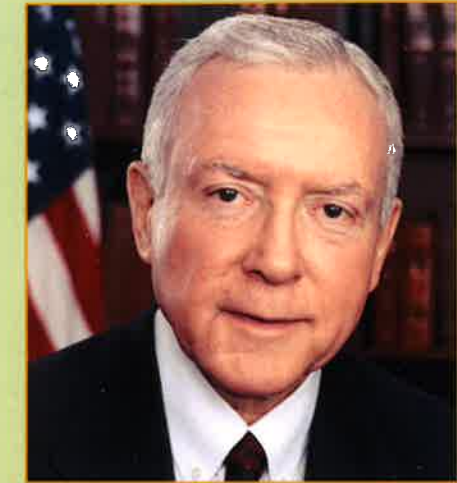
Family Voices gratefully acknowledges the reception supporters:

Sponsors:

- **The Honorable Michelle Lujan Grisham, U.S. House of Representatives, New Mexico**
- **Child and Adolescent Health Measurement Initiative (CAHMI)**
- **The Children's Hospital Association**
- **Association of Maternal and Child Health Programs (AMCHP), Contributor**



The Honorable Tom Harken  
U.S. Senate, Iowa



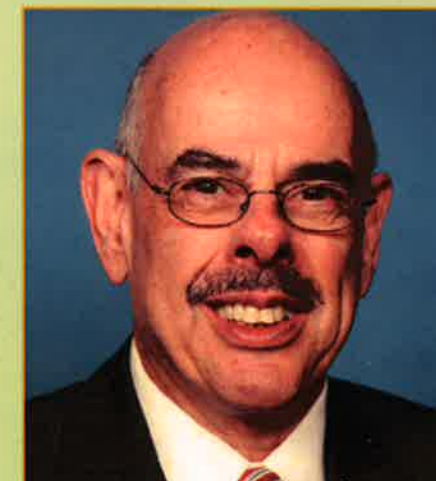
The Honorable Orrin Hatch  
U.S. Senate, Utah



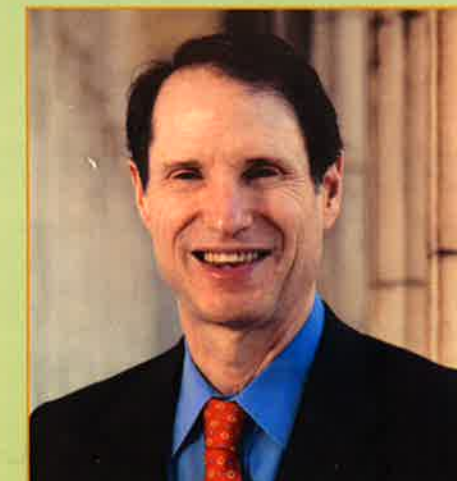
The Honorable Robert Menendez  
U.S. Senate, New Jersey



The Honorable Frank Pallone, Jr.  
U.S. House of Representatives, New Jersey



The Honorable Henry Waxman  
U.S. House of Representatives, California



The Honorable Ron Wyden  
U.S. Senate, Oregon

## SCHEDULE

### Tuesday, May 20: Leadership Meeting

The Capitol Room (9th floor)  
McDermott Building  
500 North Capitol Street

➤ 8:00am – 5:00pm

#### REGISTRATION OPEN

➤ 8:00am - 8:50am

#### CONTINENTAL BREAKFAST - ROUND TABLES

##### ➤ Health & Wellness: Self-Care for Staff

Breathe! This is your hour to explore ways to take care of your health and well-being. As parents and family leaders, our responsibilities require much of us—physically and emotionally. Our run is a long distance one, not a sprint! So let's join together to share ideas for rest, renewal, regeneration and inspiration.

##### Facilitators:

Leslie Carroll, Director, Project IMPACT, FamilyVoices  
Carmina Cirioli, Co-Executive Director, PATH Parent to Parent/FamilyVoices of Connecticut

##### ➤ Staff Development

Keeping Up With Changes: We will use this opportunity to discuss strategies for keeping staff up-to-date in a changing health care environment.

##### Facilitators:

Faye Manaster, Family-to-Family Director, FamilyVoices of Illinois  
Rhiannon Traigle, Executive Director, Bayou Land Families Helping Families, Louisiana

##### ➤ Rural Families: Joys and Challenges

Living in a rural or frontier area presents unique challenges for families of CYSHN. We welcome family leaders from rural/frontier communities to discuss creative ways to help families overcome those challenges. The objective of this roundtable is to draft a family tip sheet of parent-to-parent advice for raising CYSHN in rural communities. Bring us your best ideas and resources!

##### Facilitators:

Tamara Bakewell, Project Coordinator, Oregon Family to Family Health Information Center  
Amy Westfall, Program Manager, Stone Soup Group, Alaska



##### ➤ The National Center for Children's Vision and Eye Health (NCCVEH), a project of Prevent Blindness

Join us to learn about eye health resources available to families and the professionals who serve them, the latest information on the vision Essential Health Benefit included in the Affordable Care Act, and to tell us what is happening in your state to support eye health for children.

##### Facilitators:

Kira Baldonado, Director, National Center for Children's Vision and Eye Health  
Alison Manson, Director of Governmental Affairs for Prevent Blindness  
Melissa Vickers, IMPACT Project Coordinator, FamilyVoices

##### ➤ Family Centered Care Assessment (FCCA)

Families have much to contribute to the understanding and measurement of family-centered care. Come learn more about this new quality assessment tool based on families' experiences that is ready to be used in provider settings.

##### Facilitator:

Nora Wells, Co-Director, FamilyVoices National Center for Family/Professional Partnerships

##### ➤ Let's Talk Nuts and Bolts of Social Media!

Have more questions after the social media session or didn't get to attend at all? Join this roundtable discussion to hear what others are doing and pick up tips to expand your social media presence.

##### Facilitators:

Rylin Rodgers, Director, FamilyVoices Indiana  
Steve Viehweg, President, FamilyVoices Indiana



<http://www.infanthearing.org/>

➤ 9:00am - 10:30am

### PLENARY: ENVISIONING THE FUTURE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS & THEIR FAMILIES – POSITIONING FAMILY LEADERSHIP AT THE STATE AND NATIONAL LEVELS

What is the future going to look like for children and youth with special health care needs and their families? Three national experts will address this question from various perspectives to assist our national and state organizations position themselves to be viable and responsive to meet future needs: young families, youth leadership, cultural diversity, and state perspective.

#### Welcome & Introductions:

Cristine Marchand, Executive Director, Family Voices

#### Moderator:

Leolinda Parlin, Treasurer, Family Voices Board of Directors

#### Speakers:

Michael Lu, MD, MS, MPH, Associate Administrator, Maternal and Child Health Health Resources and Services Administration U.S. Department of Health and Human Services

Sharon Lewis, Acting Principal Deputy Administrator, Administration for Community Living Commissioner, Administration on Intellectual and Developmental Disabilities

Celinda Lake, President, Lake Research Partners

#### Sponsor:

Hawai'i Pediatric Association Research and Education Foundation

➤ 10:30am - 10:45am

### BREAK

➤ 10:45am - Noon

### ENVIRONMENTAL SCAN: PRESENTATION AND REACTOR PANEL: CHALLENGES AND OPPORTUNITIES

Family Voices engaged multiple perspectives from state and national stakeholders to provide guidance on critical issues facing children and youth with special health care needs and their families, state challenges, and the Family Voices organizational structure. These results will assist states in meeting future challenges and guide the National Family Voices Board's strategic planning efforts. A reactor panel has been selected to highlight key findings as seen from the future generation: youth leader, young families, state perspective, and cultural and linguistic diversity.

#### Presenter:

Molly Cole, President, Family Voices Board of Directors

#### Moderator:

Cristine Marchand, Executive Director, Family Voices

#### Reactor Panel:

Tara Townsend, Family Support Coordinator, Rhode Island Parent Information Network – Family Leader Perspective

Jennifer Thomas, Youth Development Specialist, National Collaboration on Workforce and Disability, Institute for Educational Leadership – Youth Perspective

Wendy Jones, Research Instructor and Director, Children & Youth with Special Health Care Needs Project, National Center for Cultural Competence, Georgetown University Center for Child & Human Development – Cultural and Linguistic Diversity

Melanie Kaufmann, Executive Director, Family TIES of Nevada – State Perspective

### TUESDAY PLENARY SPEAKER BIOS

#### Michael Lu, MD, MS, MPH



Dr. Lu is Associate Administrator, Maternal and Child Health Health Resources and Services Administration U.S. Department of Health and Human Services. Dr. Lu joined HRSA from the University of California, Los Angeles Schools of Medicine and Public Health, where he was associate professor of obstetrics, gynecology and public health. Dr. Lu brings years of experience in MCH research, practice, and policy to his post at HRSA. Prior to his appointment to head up MCHB, Dr. Lu chaired the Secretary's Advisory Committee on Infant Mortality. He has served on two Institute of Medicine (IOM) Committees (Committee on Understanding Premature Birth and Assuring Healthy Outcomes, and Committee to Reexamine IOM Pregnancy Weight Guidelines), and the Centers for Disease Control and Prevention Select Panel on Preconception Care. While at UCLA, Dr. Lu was a lead investigator for the National Children's Study. He also led a project to monitor and improve the quality and safety of maternity care in California. He was best known for his research on racial-ethnic disparities in birth outcomes, and his visionary leadership on life course. Dr. Lu taught obstetrics and gynecology at the David Geffen School of Medicine at UCLA, and maternal and child health at UCLA School of Public Health. He has received numerous awards for his teaching, including Excellence in Teaching Awards from the Association of Professors of Gynecology and Obstetrics. As an obstetrician, Dr. Lu has attended over a thousand births, and has been voted one of the Best Doctors in America since 2005.

#### Sharon Lewis



Ms. Lewis is Acting Principal Deputy Administrator, Administration for Community Living Commissioner, Administration on Intellectual and Developmental Disabilities. Sharon Lewis serves in the dual roles of Acting Principal Deputy Administrator of the Administration for Community Living and Commissioner of the Administration on Intellectual and Developmental Disabilities (AIDD), within the Administration for Community Living. From March 2010 to April 2012, Ms. Lewis served as the Commissioner of the Administration on Developmental Disabilities. Prior to her appointment as Commissioner, she served as the Senior Disability Policy Advisor to U.S. House Committee on Education & Labor, advising members of the Committee on legislative strategy and disability-related policy issues in education, employment and healthcare, and as a Kennedy Public Policy Fellow for U.S. Senate Subcommittee on Children & Families. Sharon is the recipient of numerous awards, including the 2010 Distinguished Leadership in National Disability Policy Award and the Consortium for Citizens with Disabilities Chairman's Award. In Oregon, Sharon worked on public policy for the Oregon Developmental Disabilities Coalition and for The Arc. She served as co-chair of the Oregon Family Action Coalition Team, founded DisabilityCompass.org and managed the Oregon Partners in Policymaking Program. Sharon is a parent to three daughters, including one with disability.

#### Celinda Lake



Celinda Lake, President of Lake Research Partners, is a prominent pollster and political strategist, with key interests in women's issues, health policy, changing demographics, immigration, and social justice. Lake Research Partners is a national public opinion and political strategy research firm founded by Celinda Lake in 1995. The firm's principals are leading information and political campaign strategists, serving as tacticians and senior advisors to a wide range of advocacy groups, labor unions, non-profits, government agencies, companies and foundations, as well as dozens of elected officials at all levels of the electoral process. The firm is national in scope, with offices in Washington, DC, New York, and California, and senior staff located in Washington, Oregon, and Virginia. Non-partisan clients include Aging with Dignity, American Cancer Society, American Lung Association, Aspen Institute, Center on Budget and Policy Priorities, Center for Health and Health Care in Schools, Community Catalyst, DC Campaign to Prevent Teen Pregnancy, Faith in Action, Institute for Health Policy Solutions, League of Women Voters, Midwest Business Group on Health, National Academy for State Health Policy, National Assembly on School-Based Health Care, National Association of Public Hospitals and Health Systems, National Breast Cancer Coalition, National Family Caregivers Association, National Hospice and Palliative Care Organization, National Partnership for Women and Families, New England Alliance for Children's Health, Partnership to Fight Chronic Disease, and many others.

➤ Noon - 1:30pm

**REGIONAL BREAKOUTS/WORKING LUNCH**

This is an opportunity to begin planning in your state and region. Please select 2-3 issues/findings from the environmental scan relevant for your region, develop ways your region can address the issues, and decide how you will follow up with one another. Please summarize your recommendations on the note cards provided at your table for the benefit of the FV National Board of Directors.

**Moderator:**

Marcia O'Malley, Vice-President, FamilyVoices Board of Directors

➤ 1:30pm - 1:50pm

**THE INSIDE SCOOP**



This session will provide you with more insight into the politics and processes for federal health policy as it impacts children with special health care needs, especially regarding access to oral health. You'll gain an insider's view on the congressional environment and tips on going to the Hill in preparation for our visits to members of Congress. Ms. Sealander is a registered lobbyist.

**Speaker:**

Karen Sealander, Legislative Counsel, McDermott, Will and Emery LLP

Ms. Sealander is legislative counsel in the law firm of McDermott Will & Emery LLP and is based in the Firm's Washington, D.C. office. A member of the Firm's Government Strategies practice, Karen focuses her practice exclusively in the health sector. Ms. Sealander has more than two decades of experience representing and counseling health care providers, health insurance plans, integrated health care delivery systems, professional associations of health care providers and others in the health sector on legislative, regulatory and legal matters. She worked extensively on the Patient Protection and Affordable Care Act, legislation enacted in March 2010 which reformed the nation's health care delivery system.

➤ 1:50pm - 2:00pm

**CONCLUDING REMARKS**

Marcia O'Malley, Vice-President, FamilyVoices Board of Directors

➤ 2:00pm - 2:30pm

**PREPARATION FOR 'FAMILY VOICES DAY ON THE HILL'**

Lynda Honberg, Director of Strategic Partnerships, FamilyVoices  
Brooke Lehmann and Janis Guerney, Policy Team, FamilyVoices

**SCHEDULE**

**Wednesday, May 21: Board/Staff Retreat**

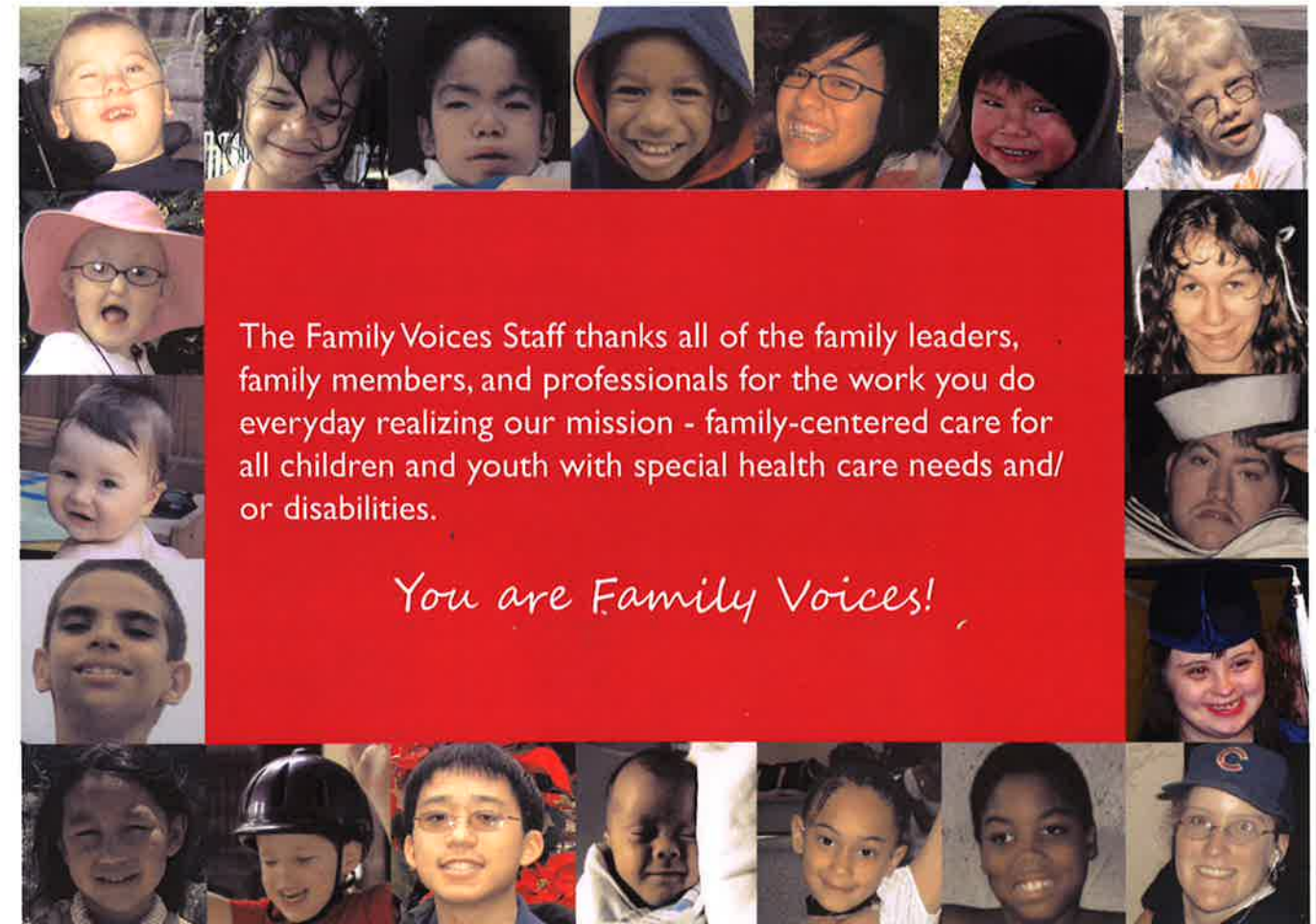
The Capitol Room (9th floor)  
McDermott Building  
500 North Capitol Street

➤ 8:00am - 2:00pm

**BOARD/STAFF STRATEGIC PLANNING MEETING (CLOSED)**

➤ 2:00pm - 2:30pm

**BOARD OF DIRECTORS MEETING (CLOSED)**



The FamilyVoices Staff thanks all of the family leaders, family members, and professionals for the work you do everyday realizing our mission - family-centered care for all children and youth with special health care needs and/or disabilities.

*You are FamilyVoices!*

## GENERAL INFORMATION

### Meeting Feedback

Your evaluation of the FamilyVoices 2014 Family Leadership Meeting is VERY IMPORTANT to us! At the end of each session, you will be asked to complete a very brief evaluation. At the conclusion of the conference please provide your overall feedback online at:

<https://www.surveymonkey.com/s/2014FVMeeting>

You will find a "Take Away" form in your folders on which you can capture ideas to implement at home.



### On-Site Technical Assistance

FamilyVoices and the National Center for Family/Professional Partnerships is pleased to offer individual, on-site technical assistance at designated times throughout the FamilyVoices Conference.

On-site TA will be available to participants who have signed up in advance of the conference. Information on assigned times will be available at the registration desk. For questions, please see Ashlee Richey, Bev Baker or Nora Wells.



### Internet Access

While in the McDermott Building, the internet may be accessed by searching for the network 'MWE' (all caps with no password).

CATALYST CENTER  IMPROVING FINANCING OF CARE for Children & Youth WITH SPECIAL HEALTH CARE NEEDS

Your heart

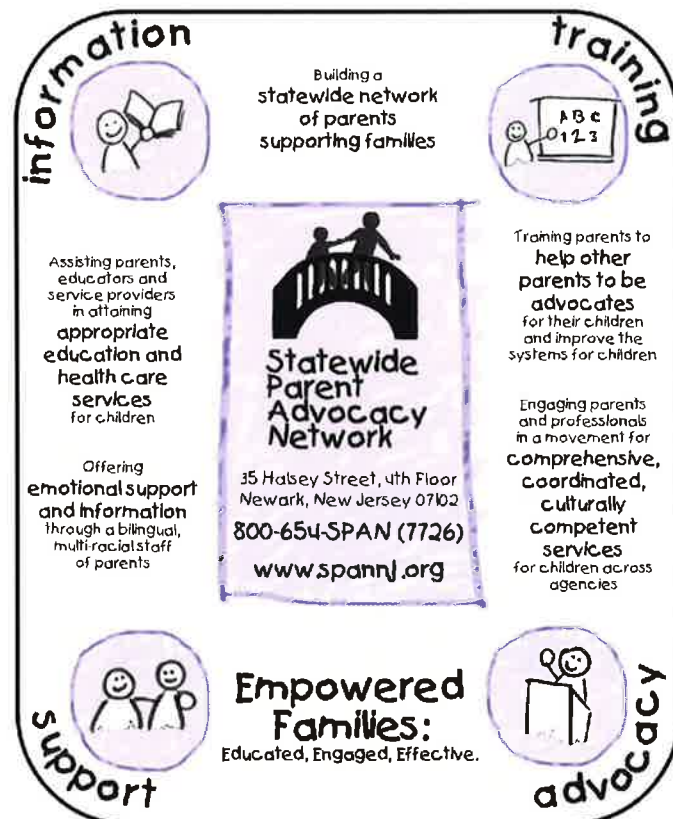
Our data



## Partnership is powerful!

Wanna dance?

Dancing with data: <http://hdwg.org/catalyst/data>



**information**  
Building a statewide network of parents supporting families  
Assisting parents, educators and service providers in attaining appropriate education and health care services for children  
Offering emotional support and information through a bilingual, multiracial staff of parents

**training**  
Training parents to help other parents to be advocates for their children and improve the systems for children  
Engaging parents and professionals in a movement for comprehensive, coordinated, culturally competent services for children across agencies

**support**

**advocacy**

**Statewide Parent Advocacy Network**  
35 Halsey Street, 4th Floor  
Newark, New Jersey 07102  
800-654-SPAN (7726)  
[www.spannj.org](http://www.spannj.org)

# LRP

 LAKE RESEARCH PARTNERS

PRECISION  
STRATEGY  
IMPACT

Over the last 19 years, Lake Research Partners (LRP) has established itself as a leader in all phases of public opinion research for public entities and private enterprises with expert services such as:

- Political Polling and Strategic Campaign Consulting
- Issue Advocacy and Message Development
- Ad Testing
- Examining Policies and Programs
- Branding and Reputation Management
- Membership Evaluation
- Corporate Affairs
- Jury Research

Celinda Lake and LRP are thrilled to be a part of the FamilyVoices Leadership Meeting and be able to participate in this important discussion around the future of children and their families and how special health care needs tie into changing demographics and family structures.

**Lake Research Partners**  
1726M St., NW  
Suite 1100  
Washington, DC 20036  
[info@lakeresearch.com](mailto:info@lakeresearch.com)  
Tel: 202.776.9066  
Fax: 202.776.9074  
[www.LakeResearch.com](http://www.LakeResearch.com)

## ABOUT FAMILY VOICES

### Our MISSION

Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through our national grassroots network, we provide families with resources and support to make informed decisions, advocate for improved public and private policies, build partnerships among families and professionals, and serve as a trusted resource on health care.

### OUR VISION

Every child and youth with special needs receives family-centered care.

### OUR PRINCIPLES

- **Family-centered care.** Because families are at the center of a child's life, they must be equal partners in decision-making and all aspects of the child's care. Family-centered care is community-based, coordinated, culturally and linguistically competent, and guided by what is best for each child and family.
- **Partnerships.** Family-centered care is based upon strong and effective family-professional relationships built within the context of families' and professionals' cultural values and practices to improve decision-making, enhance outcomes, and assure quality.
- **Quality, access, affordability and acceptability.** Children with special needs deserve primary and specialty health care that is of high quality, affordable, within geographic reach and respectful of family and community culture.
- **Health systems that work for families and children.** Health policies and systems built on a foundation of family-centered, culturally and linguistically competent care must be the standard for all children.
- **Informed families/strong communities.** Like their peers, children with special needs deserve every opportunity to enjoy a happy and healthy childhood at home in their communities. Families equipped with reliable, accurate information about ways to support their child's health, education and social development will help them grow into productive adults as defined by their personal, family and community cultural beliefs and values.
- **Self-advocacy/empowerment.** When informed and supported, young people with disabilities can make choices and advocate for themselves.



### OUR WORK

Family Voices is a national nonprofit organization that works to keep families at the center of children's health care. Founded in 1992, Family Voices has been built by a remarkable grassroots network of family and youth leaders and friends across the country. Family leaders in every state provide information, assistance, and support to families of all children and youth with special health care needs and/or disabilities, representing a wide spectrum of diagnoses and illness/health conditions. This network of family leadership is connected and supported by a national Family Voices staff and experienced peer leaders in four regions. Youth leadership is encouraged through Kids as Self Advocates (KASA), a youth self-advocacy project. Family Voices has strong partnerships with multiple professional groups to promote quality family-centered care for children and youth with special needs. Family Voices monitors federal and state legislation and provides information to help families and family leaders understand the legislative process and advocate at both the state and national levels for policies that support the complex needs and situations of families.



### OUR PROJECTS

#### NATIONAL CENTER FOR FAMILY/PROFESSIONAL PARTNERSHIPS (NCFPP)

Through the NCFPP, Family Voices increases the capacity of families, Title V and other providers to partner around full implementation of the Affordable Care Act (ACA); strengthens the primary care workforce through family/professional learning opportunities; and improves access to quality care and innovation in the areas of family-centered care, cultural and linguistic competence and shared decision making.

#### IMPACT PROJECT (IMPROVING MATERNAL CHILD HEALTH POLICIES SO ALL CHILDREN THRIVE)

Through the IMPACT Project, Family Voices assists in the development and dissemination of culturally appropriate materials focused on health and wellness promotion for all children and youth, including those with special health care needs and/or disabilities and their families. We offer information to MCH partners, health care providers, family organizations and families including such topics as prevention as a core component of the ACA, maternal and child health policies and practices for all children and youth through *Bright Futures* materials, and related health and wellness resources.

#### ENGAGING NATIVE AMERICAN AND SPANISH-SPEAKING FAMILIES & SHARING FAMILY WISDOM TO REDUCE CHILDHOOD OBESITY

Funded by the Patient Centered Outcomes Research Institute (PCORI), this project focuses on developing partnerships in two Western states to empower families and build a community interested in promoting research on childhood obesity. We are working with State Affiliated Organizations in Idaho and Washington states, focusing on Spanish speaking and Native American families.

#### BRIGHT FUTURES

Working in partnership with the American Academy of Pediatrics, Family Voices IMPACT Project staff serve on the Bright Futures Steering Committee, as well as the Infancy Expert Panel for the 4th Edition of the *Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents*.

**LIFE COURSE AND THE SOCIAL DETERMINANTS OF HEALTH**

As a member of the MCH Life Course Research Network, FamilyVoices IMPACT staff are providing the family perspective to the IMPACT website, as well as life course materials and guidelines being developed as part of a restructure and refocus of MCHB. We are writing a journal article, "Life Course Health Development Theory and Research in Partnership with Families."

**TITLE V**

FamilyVoices provides training and mentoring to family members who review the State Title V Block Grants each summer.

**CARE COORDINATION FACILITATION FOR CYSHCN IN NEW MEXICO**

In partnership with Parents Reaching Out and Blue Cross/Blue Shield of New Mexico, FamilyVoices has provided information to families from Native American communities across New Mexico to help them better understand and avail themselves of their care coordination options under the Affordable Care Act (ACA).

**DATA RESOURCE CENTER (DRC)**

Through a partnership with the Child and Adolescent Measurement (CAHMI), FamilyVoices contributes the perspective of families to the development and dissemination of the DRC website and products, provides input to the redesign of the National Surveys, and provides family perspective on the development of tools to prepare families for well child health visits.

**FAMILY-CENTERED CARE ASSESSMENT TOOL (FCCA)**

The FCCA is a quality measurement tool that has been developed by FamilyVoices in partnership with expert university researchers through an extensive research protocol. The 24-question tool has been documented to have high reliability and evidence of empirical validity. It expands areas of quality measurement to important new content areas in decision-making interactions, family support, community services, and cultural competence. FamilyVoices is partnering with the AAP to test the FCCA in pediatric practices.

**FLU PREVENTION AND TREATMENT**

At the request of the Centers of Disease Control (CDC) FamilyVoices collaborated in the collection of information from families of CYSHCN about their understanding and attitudes about flu treatments and vaccines. A survey, co-developed by CDC and FamilyVoices, found the startling results that many CYSHCN with nerurologic conditions did not receive the flu vaccine and that many pediatricians did not recognize intellectual disability as a high-risk condition for the flu. FamilyVoices worked with CDC to educate providers and families on the risks of flu for CYSHCN.

**CHILDREN'S VISION HEALTH EDUCATION**

FamilyVoices has worked with the National Center for Children's Vision and Eye Health to provide input into the design of educational materials for families on the benefits of vision screening and dissemination of such information.

**GENETICS EDUCATION**

In partnership with the Genetics Alliance and Parent to Parent USA, FamilyVoices has contributed to education and outreach materials and programs as part of the National Genetics Education and Consumer Network (NGECN) project.

**KASA**

Kids As Self Advocates (KASA) is a national project created by youth for youth with special health care needs and/or disabilities to share information among their peers to increase their knowledge and experiences enabling them to become more independent. KASA youth provide information to health care professionals, policymakers, and others to voice their issues, leading to discussions about how to help each other succeed.

**OUR PARTNERSHIPS with STATE FAMILY LEADER ORGANIZATIONS**

At the core of FamilyVoices are grassroots families supported by the Family-to-Family Health Information Centers (F2Fs) and State Affiliated Organizations (SAOs.) Through this extensive network, we enjoy unique benefits: National FamilyVoices is connected to individual families from whom we learn and to whom we can provide information; F2Fs and SAOs receive critical policy guidance and technical assistance from FamilyVoices; and the full network shares resources, provides mentorships, and supports one another to form an effective and trusted "family voice" to guide health policy at all levels of our health care system.

F2Fs are family-staffed organizations that provide information, education, technical assistance and peer support to families of CYSHCN and professionals. The F2F network is comprised of organizations in every state and the District of Columbia, each of which receives funding from the Health Resources and Services Administration, Maternal Child Health Bureau through a competitive grant process. F2Fs are supported with technical assistance, training, and resources through FamilyVoices National Center for Family/Professional Partnership.

SAOs are nonprofit, family-led advocacy organizations committed to the mission, vision, and principles of FamilyVoices. SAOs engage in systems change in their state and at the national level to improve the quality of health care for CYSHCN and their families. There are 43 SAOs nationwide. Most F2Fs are also SAOs.

FamilyVoices is grateful to our network partners who are committed to keeping the voices of families at the heart of children's health care.

AK: Stone Soup Group (SAO, F2F)	MS: FamilyVoices of Mississippi - Family 2 Family (SAO, F2F)
AL: FamilyVoices of Alabama (SAO, F2F)	MT: Parents Lets Unite for Kids (PLUK) (SAO, F2F)
AR: Arkansas Disability Coalition (F2F)	NC: Exceptional Children's Assistance Center (SAO, F2F)
AZ: Raising Special Kids (SAO, F2F)	ND: FamilyVoices of North Dakota (SAO, F2F)
CA: Support for Families of Children with Disabilities (SAO, F2F)	NE: PTI Nebraska (SAO, F2F)
CO: FamilyVoices Colorado (SAO, F2F)	NH: New Hampshire FamilyVoices (SAO, F2F)
CT: PATH Parent to Parent of Connecticut (SAO, F2F)	NJ: Statewide Parent Advocacy Network of NJ (SAO, F2F)
DC: FamilyVoices of DC (SAO)	NM: Parents Reaching Out- PRO (SAO, F2F)
DC: Advocates for Justice and Education (F2F)	NV: Family TIES of Nevada (SAO, F2F)
DE: Delaware FamilyVoices (SAO, F2F)	NY: Parent to Parent of New York State (SAO, F2F)
FL: Family Network on Disabilities (SAO, F2F)	OH: FamilyVoices of Ohio (SAO, F2F)
GA: Parent to Parent of Georgia (F2F)	OK: Oklahoma Family Network (SAO, F2F)
HI: Hilopa'a Family to Family Health Information Center (F2F)	OR : Oregon Family to Family Health Information Center (F2F)
IA: ASK Resource Center (SAO, F2F)	PA: Parent Education & Advocacy Leadership Center (SAO, F2F)
ID: Idaho Parents Unlimited, Inc. (SAO, F2F)	RI: Rhode Island Parent Information Network (SAO, F2F)
IL: Arc of Illinois F2FHIEC, The (SAO, F2F)	SC: Family Connection of South Carolina, Inc. (SAO, F2F)
IN: FamilyVoices Indiana (SAO, F2F)	SD: South Dakota Parent Connection (SAO, F2F)
KS: Families Together, Inc. (SAO, F2F)	TN: FamilyVoices of Tennessee at Tennessee Disability Coalition (SAO, F2F)
KY: Kentucky Commission for Children with Special Health Care Needs (SAO, F2F)	TX: Texas Parent to Parent (SAO, F2F)
LA: Bayou Land Families Helping Families (SAO, F2F)	UT: Utah FamilyVoices (F2F)
MA: Massachusetts FamilyVoices at Federation for Children with Special Needs (SAO, F2F)	VA: Family to Family Network of Virginia (Center for Family Involvement @ VCU) (F2F)
MD: Parents Place of Maryland (SAO, F2F)	VT: Vermont Family Network (SAO, F2F)
ME: Maine Parent Federation (F2F)	WA: PAVE/FamilyVoices of Washington (SAO, F2F)
MI: Michigan FamilyVoices (SAO)	WI: FamilyVoices of Wisconsin (SAO, F2F)
MI: Michigan Public Health Institute (F2F)	WV: WV Parent Training and Information, Inc. (SAO, F2F)
MN: FamilyVoices of Minnesota (SAO)	WY: FamilyVoices of Wyoming at UPLIFT (SAO)
MN: Pacer Center (F2F)	WY: Wyoming Institute for Disabilities (WIND) (F2F)
MO: Missouri Family-to-Family Resource Center at UMKC-IHD (F2F)	

## OUR LEADERSHIP

### BOARD OF DIRECTORS:

- Molly Cole, President  
Director, Connecticut Council on Developmental Disabilities
- Marcia O'Malley, Vice-President  
Former Executive Director, Family TIES of Nevada
- Leolinda Parlin, Treasurer  
Project Director, Hawai'i Pediatric Association Research and Education Foundation
- Grace Pushparany Williams, Secretary  
Family Leader and Advocate, Bowie, MD
- Julie Beckett  
Co-Chair of the Parent Advisory Group with the Section on Home Care under the American Academy of Pediatrics

### STAFF:

- Cristine Marchand, Executive Director  
Lynda Honberg, Director of Strategic Partnerships  
Lacey Keene, Director of Finance and Administration  
Natasha Tapia, Financial Administrative Assistant  
Cynthia Gelien, Administrative Assistant  
Trish Thomas, Director of Diversity and Outreach  
Leslie Carroll, IMPACT Director  
Melissa Vickers, IMPACT Program Coordinator  
Nora Wells, NCFPP Co-Director  
Bev Baker, NCFPP Co-Director  
Ashlee Richey, NCFPP Program Assistant

### 2014 FAMILY LEADERSHIP PLANNING COMMITTEES:

- Diana Autin  
Bev Baker  
Julie Beckett  
Leslie Carroll  
Cynthia Gelien  
Latisha Hawkins  
Jessica Hawks  
Lynda Honberg  
Barbara Katz  
Lacey Keene  
Cristine Marchand  
Jill McCormack  
Marcia O'Malley

- Renee Turchi, M.D.,  
Assistant Professor, Drexel University School of Public Health  
Director, PA Medical Home Program (EPIC IC)  
Director, Center for Children with Special Health Care Needs, St. Christopher's Hospital for Children
- Peters D. Willson  
Senior Specialist, Policy and Constituency Issues, Association of American Medical Colleges
- Josie Woll  
Retired, Executive Director, Family Voices of Hawaii, Honolulu, HI

### CONSULTANTS:

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Suzanne Bronheim, FCC Research Project  
Peggy Curran, IT and Design Consultant  
Janis Guerney, Policy Co-Director  
Clarissa Hoover, Research Consultant  
Brooke Lehmann, Policy Co-Director  
Mary Jo Paladino, National Field Co-Coordinator  
Sherry Richardson, NICHQ WISCH  
Carlos Romero, Evaluator  
Stephen Zyzanski, FCC Research Project



**NATIONAL CENTER**  
*for Children's Vision & Eye Health*

**AT PREVENT BLINDNESS**

**OUR MISSION:**  
*To improve children's vision through strong partnerships, sound science, and targeted public policy*

[nationalcenter.preventblindness.org](http://nationalcenter.preventblindness.org)

Evidence-based best practices



Technical assistance for screeners and educators



Educational resources for families







**One in Five Families with Children  
Has at Least One Child with Special Health Care Needs**

**Join FamilyVoices National Membership & Public Awareness Campaign & Make a Difference**

**Did You Know?\***

- More than one in five families has at least one child with special health care needs – 23% of families.
- Approximately 14.6 Million children ages 0-17 years in the US have special health care needs (SHCN). That's nearly 20% (19.8%).
- The health care needs of these children may be physical, developmental, behavioral or emotional and represent a wide range of conditions including autism, cerebral palsy, developmental delay, intellectual disabilities, depression, learning disabilities, and epilepsy.
- Children with SHCN often have more than one condition and functional difficulties in more than one area that impacts their daily lives, such as breathing, communicating, chronic pain, learning, moving around, behavior, or challenges in making and keeping friends.
- Their families typically experience greater stress, struggling to meet the needs of their child in a maze of multiple and complex systems of care. Many families find that insurance is not adequate, care coordination is ineffective, and referrals are difficult. Families of children with SHCN are less likely to have family-centered health care.



**FamilyVoices Makes a Difference**

Through our national office and 43 state affiliates, we directly impact the lives of children and youth with special health care needs and their families.

- We provide information, training, and support to thousands of families and professionals throughout the country about current issues in health care—the Affordable Care Act, Medicaid, Family-Centered Care, Healthy Lifestyles for Children & Youth to Combat Obesity, Transition from Pediatric Care, Genetics, and more.
- We give families tools and information to make informed decisions about their children's health care. Our national monthly and quarterly publications reach over 2,000 individuals.
- We offer 1:1 family support, peer mentoring, and leadership development.
- Our national office works at the federal level with Congress and others to ensure important programs are funded and that health policy is family-centered; our state affiliates impact programs and policies in their own states, ensuring that the voices of families are heard.

**Join Us!**

Go to [www.familyvoices.org](http://www.familyvoices.org). Membership costs range from \$15 (students) to organizational memberships based on budget size. Memberships for youth with disabilities under age 24 are free. State affiliates retain 60% of each membership fee paid by members within their state.

**One in Five - Get the Word Out!**

Order and wear buttons at public events, information fairs, membership meetings, trainings and in your community. Tell others about the One in Five families.

\*Child and Adolescent Health Measurement Initiative (2013). "Who Are Children with Special Health Care Needs (CSHCN)." Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Available at [www.childhealthdata.org](http://www.childhealthdata.org). Revised 4/15/13.

**POLLY ARANGO**  
Mentoring Initiative

**Supporting a New Generation of Family Leaders of Cultural and Linguistic Diversity**

The Polly Arango Mentoring Initiative seeks to support FamilyVoices State Affiliates in preparing families from diverse cultural and linguistic backgrounds to join a new generation of family leaders that reflects the growing diverse populations within states and our nation, while building the leadership and advocacy of FamilyVoices' State Affiliate Organizations (SAOs) at the state level.

Polly Arango, beloved mother, friend and founder of FamilyVoices, was a passionate advocate for children with special health care needs and their families. Polly served as the first FamilyVoices Executive Director, which now has active state affiliates across the country.

Polly's vision for a nationwide, empowered and vocal voice of families includes the voices of families from diverse cultural and linguistic backgrounds. Polly cultivated new leaders and envisioned the leadership of FamilyVoices at the state and national levels to reflect the richness and diversity of our nation. Leadership development through mentoring was one of Polly's long-standing passions. To establish a lasting memorial to Polly, FamilyVoices will use funds from the Polly Arango Memorial Fund to establish a mentoring program. The mentoring program will support the growth of the FamilyVoices organization through the development and support of emerging family leaders from culturally and linguistically diverse backgrounds.



There are two funding opportunities for State Affiliates in Good Standing:

- 3-4 SAOs that wish to conduct Family Leadership & Mentoring for Families of Cultural & Linguistic Diversity will be selected based on an application process. Up to \$5,000 per state.
- 3-4 coaches from SAOs that wish to serve as coaches/mentors for the states selected to conduct Family Leadership & Mentoring for Families of Cultural & Linguistic Diversity. \$1,000 per state mentored.

**Projects are one year. Applications Due: July 1, 2014. Selection by August 1, 2014. Funding Begins: September 1, 2014. Applications are available at [www.familyvoices.org](http://www.familyvoices.org) or at the 2014 Family Leadership Meeting.**

FAMILY VOICES®

*Thank You to the Dedicated Family Voices Team!*

Thank you to the National Family Voices Team for your passion, commitment to our mission, and exemplary work. The 2014 Family Leadership Meeting is made possible by the hard work of national staff and consultants along with volunteers and family leaders throughout the country. Throughout this transition year at Family Voices, we have appreciated the team's support, new ideas and continued dedication.

*Kudos to the Staff:*

Bev Baker, Leslie Carroll, Cynthia Gelien, Lacey Keene, Ashlee Richey, Natasha Tapia, Trish Thomas, Melissa Vickers, Nora Wells

*and Consultants:*

Diana Autin, Peggy Curran, Janis Guernsey, Clarissa Hoover, Brooke Lehmann, Mary Jo Paladino

from  
*Cristy Marchand and Lynda Honberg*  
Co-Directors



**Congratulations, Anna, on your moving to your new home!**  
Mike and Peggy Curran



Family Voices Indiana thanks Mary Jo Paladino for Board Service 2007-2013.



*To our staff for their dedication to New Hampshire families*  
-Martha-Jean and Terry



*Family Voices Angels*  
Dave Woll,  
Polly and Nick Arango,  
and Katie Beckett  
*We miss you dearly.*



**Congratulations, Sarah, on graduating from the University of Maryland. We are so proud of all your achievements - especially for the kids!**  
Ron and Lynda Honberg

We lovingly remember the children of members of the Family Voices network who passed away during this year. We extend our deepest sympathy for the loss of these and other family members and friends. We are grateful for the joy their lives contributed to their families and communities. They live on forever in our memories.

*Latoya, daughter of Phyllis Landry  
Becky, daughter of Grace Sisco  
Bridget, daughter of Maureen Mitchell  
Nick, son of John and Polly Arango*

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*(pou-er-ful pahrt-ner-ships), noun*

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