The Power of Partnerships

Family Leadership Meeting
May 18-21, 2014

CONFERENCE PROGRAM BOOK

FAMILY VOICES
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.

McDermott Will & Emery

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CONFFERENCE SPONSORS

Family Voices 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.

Family Voices 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
- Family Voices 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
- Family Voices Staff
- Family Voices of Indiana
- New Hampshire Family Voices
- Youth Transitions Collaborative
- Paul Newcheck
BECOME A CHAMPION 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.

HERE’S HOW IT WORKS:

- Join the network and become a champion
- Learn about issues that affect kids’ health
- Tell your story about why health care matters to kids
- Take action by writing your members of Congress
- Share what you're learning with others on social media

For more information visit www.speaknowforkids.org.

The CAHMI is honored to partner with Family Voices to promote the early and lifelong health of children, youth, and families.

Find us on the web at:
- www.ChildHealthData.org
- www.WellVisitPlanner.org
- 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)

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**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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**YOUTH TRANSITIONS COLLABORATIVE**
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MONDAY PLENARY SPEAKER BIOS

Jeff Levi

Dr. 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 F. Wilson appointed him chair of the Advisory Group. Dr. Levi is also Professor of Health Policy at 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 a 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 and 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 “Eachtown Commission.” On the Paper 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, MEd, 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
LeQuanta 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 Austin, National Field Co-Coodinator, Family Voices
Mary Jo Paladino, National Field Co-Coodinator, Family Voices

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

1:20pm - 1:30pm
BREAK
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 fees 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 Austin, 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, UMCKC-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 underway 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 - 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
LeQuanta 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 Ross, Director, NJ Family to Family Health Information Center; Director Innovative Evidence-Based Practices Project, Statewide Parent Advocacy Network of New Jersey
Marilyn 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 your 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

Doodle wishes you a productive meeting and reminds you to take note of breaks.

May 18-21, 2014 Washington, D.C.
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, Family Voices
Carmina Cirillo, Co-Executive Director, PATH Parent to Parent/Family Voices 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 Manzer, Family-to-Family Director, Family Voices of Illinois
Rhannon Traige, 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 Bakeell, Project Coordinator, Oregon Family to Family Health Information Center
Amy Westfall, Program Manager, Stone Soup Group, Alaska

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

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, Family Voices

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, Family Voices 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, Family Voices Indiana
Steve Viehweg, President, Family Voices Indiana

FAMILY VOICES
Network, Members, Volunteers and Staff

Thank you for all you do to keep families at the center of children’s health!
From our hearts to yours,
Board of Directors

NCHAM
National Center for Hearing Assessment and Management
Utah State University
http://www.infanthearing.org/

May 18-21, 2014 Washington, D.C.
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 themselves to be visible 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

TUESDAY PLENARY SPEAKER BIOS

Michael Lu

Dr. Lu is Associate Administrator, Maternal and Child Health Health Resources and Services Administration (HRSA). Dr. Lu joined HRSA from the University of California, Los Angeles School 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 Resiexamine 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 (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 Subcommittees 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 a 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 advisors 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, D.C., 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 on Health and Health Care in Schools, Community Change, D.C. 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.
The Power of Partnerships

SCHEDULE

Wednesday, May 21: Board/Staff Retreat
The Capitol Room (9th floor)
McDermott Building
500 North Capitol Street

> Noon - 1:30 pm
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, Family Voices Board of Directors

> 1:30 pm - 1:50 pm
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.

> 1:50 pm - 2:00 pm
CONCLUDING REMARKS
Marcia O'Malley, Vice-President, Family Voices Board of Directors

> 2:00 pm - 2:30 pm
PREPARATION FOR ‘FAMILY VOICES DAY ON THE HILL’
Lynda Honberg, Director of Strategic Partnerships, Family Voices
Brooke Lehmann and Janis Guerney, Policy Team, Family Voices

SCHEDULE

> 8:00 am - 2:00 pm
BOARD/STAFF STRATEGIC PLANNING MEETING (CLOSED)

> 2:00 pm - 2:30 pm
BOARD OF DIRECTORS MEETING (CLOSED)

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

You are Family Voices!
**GENERAL INFORMATION**

**Meeting Feedback**
Your evaluation of the Family Voices 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/2014FVMMeeting](https://www.surveymonkey.com/s/2014FVMMeeting)

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

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**On-Site Technical Assistance**
Family Voices and the National Center for Family/Professional Partnerships is pleased to offer individual, on-site technical assistance at designated times throughout the Family Voices 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.

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**Internet Access**
While in the McDermott Building, the internet may be accessed by searching for the network ‘MVE’ (all caps with no password).

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**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 Family Voices 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
1726 M St., NW
Suite 1100
Washington, DC 20036
info@lakeresearch.com
Tel: 202.776.9066
Fax: 202.776.9074
www.lakeresearch.com

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

May 18-21, 2014 Washington, D.C.
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, Family Voices 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."

TITHE
Family Voices 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, Family Voices 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 (CAHM), Family Voices 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 Family Voices 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. Family Voices 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) Family Voices 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 Family Voices, found the startling results that many CYSHCN with neurologic conditions did not receive the flu vaccine and that many pediatricians did not recognize intellectual disability as a high-risk condition for the flu. Family Voices worked with CDC to educate providers and families on the risks of flu for CYSHCN.

CHILDREN'S VISION HEALTH EDUCATION
Family Voices 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, Family Voices has contributed to education and outreach materials and programs as part of the National Genetics Education and Consumer Network (NGECon) 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 Family Voices 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 Family Voices 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 Family Voices; 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 Family Voices National Center for Family/Professional Partnership.

SAOs are nonprofit, family-led advocacy organizations committed to the mission, vision, and principles of Family Voices. 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.

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

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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. Wilson
Senior Specialist, Policy and Constituency Issues, Association of American Medical Colleges

Josie Wall
Retired, Executive Director, Family Voices of Hawaii, Honolulu, HI

CONSULTANTS:
Lauren Agoratus, Blog Contributor
Carolyn Althouse, NCPPP Consultant
Diana Austin, National Field Co-Coordinator
Suzanne Bronhein, FCC Research Project
Peggy Curran, IT and Design Consultant
Janis Guernsey, 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

2014 FAMILY LEADERSHIP PLANNING COMMITTEES:
Diana Austin
Bev Baker
Julie Beckett
Leslie Carroll
Cynthia Gellen
Latisha Hawkins
Jessica Hawks
Lynda Honberg
Barbara Katz
Lacey Keene
Cristine Marchand
Jill McCormack
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nationalcenter.preventblindness.org

Evidence-based best practices
Technical assistance for screeners and educators
Educational resources for families

May 18-21, 2014 Washington, D.C.
One in Five Families with Children
Has at Least One Child with Special Health Care Needs

**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.

**Join Us!**

Go to 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.

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

The Polly Arango Mentoring Initiative seeks to support Family Voices 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 Family Voices' State Affiliate Organizations (SAOs) at the state level.

Polly Arango, beloved mother, friend and founder of Family Voices, was a passionate advocate for children with special health care needs and their families. Polly served as the first Family Voices 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 Family Voices 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, Family Voices will use funds from the Polly Arango Memorial Fund to establish a mentoring program. The mentoring program will support the growth of the Family Voices 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 mentor.

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 or at the 2014 Family Leadership Meeting.
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 Galen, Lacey Keene, Annette Richey, Natasha Taipa, Erin Thomas, Melissa Vickers, Nina Wells

and Consultants:
Diane Aubin, Peggy Curran, Janie Giamney, Clarissa Hoover, Brooke Lehmann, Mary Jo Paladino

from
Cristy Marchand and Lynda Honberg
Co-Directors

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.

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

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

Congratulations, Anna, on your move to your new house!
Mike and Peggy Curran
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 Sicca
Bridget, daughter of Maureen Mitchell
Nick, son of John and Polly Aronga

Powerful Partnerships
(pou-er-fuh partnering), noun
1. The result of families and providers working together to improve care for children and youth.
2. A key component of NICHQ’s approach to improving children’s health for over a decade.

NICHQ
National Institute for Children’s Health Quality
Improving Children’s Health Together
www.nichq.org

AMCHP
ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS
A national resource, partner and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs
http://www.amchp.org

DeLong Lithographics
is proud to assist Family Voices with its 2014 National Conference printed materials
Whatever you want to say...

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www.p2pusa.org
info@p2pusa.org