

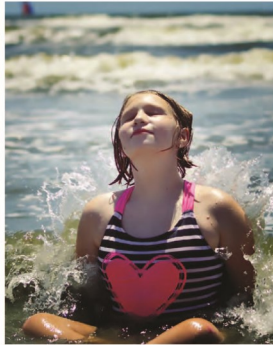
2019 FAMILY VOICES LEADERSHIP CONFERENCE



FAMILY VOICES[®]

Awards Reception

MAY 9, 2019 • HART SENATE OFFICE BUILDING



THE FAMILY VOICES VISION AND MISSION

Vision

With families at the center of health care, all children and youth reach their full potential and health disparities are eliminated.

Mission

Family Voices is a national grassroots-network organization of families and friends of children and youth with special health care needs and disabilities, **that promotes partnership with families**—including those of cultural, linguistic and geographic diversity—**in order to improve healthcare services and policies for children.**

Values

Family Voices believes in:

- ♥ Social justice and the promotion of health equity
- ♥ Authentic family-centered care that recognizes family as the center of a child's life and as an equal partner in decision-making about all aspects of the child's care
- ♥ Effective family/professional partnerships at the local, state, and national level
- ♥ Inclusion and connection of underserved families representing the cultural, linguistic and geographic diversity of the country
- ♥ Connected and informed family and youth leaders as powerful change agents
- ♥ Children and youth with special needs and their families becoming empowered self-advocates
- ♥ Family engagement in prevention, health and wellness in clinical and community settings.



AGENDA

May 9, 2019
Hart Senate Office Building

- 5:30 PM** **Meet and Greet**
We look forward to welcoming our Members of Congress and their Staffers as they arrive
- 6:00 PM** **Welcoming Remarks**
Deborah Klein Walker, President, Family Voices Board of Directors
- Sponsorship Recognition**
Nora Wells, Executive Director, Family Voices
 Children's Hospital Association, Aimee Ossman
 American Academy of Pediatrics, Debra Waldron
 Conference Sponsors
- 6:30 PM** **Honoring *Champions of Children's Health***
*Nanfi Lubogo, Family Voices Board of Directors, PATH/
Family Voices of CT*
- Award to Honoree *Renee Turchi, MD***
*Presented by Susan Colburn, Director, Family Voices of
Alabama*
- Award to Honoree *Georgetown Center for Children
and Families***
*Presented by Shauna Signorini, Oregon Family to Family
Health Information Center*
- 6:45 PM** **Welcoming: Territorial and Tribal F2Fs**
Leticia Manning, HRSA/MCHB
Maria Isabel Frangenberg, Glenn Gabbard, Family Voices
- Family Voices Staff Recognition**
Nora Wells
- Board and Network Recognition**
Deborah Klein Walker, Nanfi Lubogo
- 7:00 PM** **Closing Remarks**
Deborah Klein Walker

Please enjoy the refreshments at the ice cream bar!

CHAMPION OF CHILDREN'S HEALTH



Renee Turchi, MD, MPH, FAAP

Family Voices is honored to recognize Renee Turchi, MD, MPH, FAAP with this award as a *Champion of Children's Health*. As both a beloved practicing pediatrician and a highly respected researcher, Dr. Turchi has devoted herself to improving the care of children and youth with special health care needs (CYSHCN), particularly those with medical complexity, by authentically partnering with families. Dr. Turchi is a visionary who puts her visions in to action. Families and professionals across the country look to her for guidance in implementing medical homes, family-centered care, and effective care coordination. As a Director on the Family Voices Board, and then as the Vice-President of the Board, Dr. Turchi devoted countless hours and invaluable counsel to help Family Voices develop. Dr. Turchi continues to be deeply committed to helping Family Voices achieve its mission of keeping families at the center of children's health care.

Dr. Turchi currently serves as a professor in the Department of Pediatrics at Drexel University College of Medicine, and in the Department of Community, Health and Prevention at Drexel University School of Public Health. She is also the Medical Director of Special Programs at St. Christopher's Hospital for Children,

where she oversees grants and program development and practices. In addition, Dr. Turchi serves as the Director of the Pennsylvania Medical Home Initiative (EPIC IC), a statewide quality improvement program for pediatric practices across the state. She engages families as essential partners in this work and visits as many pediatric practices as possible. She attends federal and state meetings in order to share information and resources, and gain knowledge to share with her Pennsylvania colleagues.

In 2017, Pennsylvania Chapter of the American Academy of Pediatrics (AAP) named Dr. Turchi as *Pediatrician of the Year*, an award given to a pediatrician “who exemplifies the ideals of the pediatric profession and participates in the type of activities that are the foundation of the AAP.” It is clear from her many roles and activities that Dr. Turchi is devoted to improving pediatric care, and the health and well-being of children and families.

Dr. Turchi earned her BA at Cornell University and her MD at the Medical College of Pennsylvania. She completed her residency, and served as chief resident, at St. Christopher’s Hospital for Children in Philadelphia. Later, she participated in the Robert Wood Johnson Clinical Scholars Program at Johns Hopkins University, where she earned her Master’s in Public Health in Epidemiology. Dr. Turchi’s research and clinical work on care coordination and children with special health care needs have been presented and published in multiple national forums.

In addition to these many achievements, Family Voices knows Dr. Turchi – Renee – as a gifted mentor, and as an incredibly kind and generous partner, devoted to the families she serves and deeply committed to the principles of authentic partnership with families. *For all that you have already accomplished, Dr. Turchi, and for all that we know you will accomplish in the future, Family Voices, on behalf of children with special needs across the country, is deeply grateful.*

CHAMPION OF CHILDREN'S HEALTH



Georgetown University
Health Policy Institute
CENTER FOR CHILDREN
AND FAMILIES

Georgetown University Center for Children & Families

Family Voices is thrilled to honor the Georgetown University Center for Children & Families as a *Champion of Children's Health*, in recognition of its outstanding efforts to ensure that all children and families have access to quality, accessible health care. Thank you to all of the superb center staff who are dedicated to this goal.

The Center for Children and Families (CCF), part of the Health Policy Institute at the McCourt School of Public Policy, is an independent, nonpartisan policy and research center with a mission to expand and improve high-quality, affordable health coverage. Founded in 2005, it is devoted to improving the health of America's children and families, particularly those with low and moderate incomes and those with special health care needs.

CCF is a go-to resource for policymakers, advocates, journalists and others interested in data-driven research on health policy. The research center has its finger on the pulse of what's happening with Medicaid and CHIP both at the national and state level. CCF provides timely, accurate analysis of data and policy proposals and identifies opportunities to preserve and strengthen coverage for children and families. Family Voices and other advocacy

organizations rely on CCF's expertise to understand complex policies and their impact on the health and well-being of children and families.

Since its inception, CCF has worked hand-in-hand with Family Voices and other organizations focused on removing financial and bureaucratic barriers to health coverage for all children and families. During the debate leading up to the passage of the Affordable Care Act in 2010, CCF published research on policy changes such as banning lifetime and annual limits and protecting children with pre-existing conditions. When threats to Medicaid emerged in negotiations over the Budget Control Act of 2011, Family Voices and CCF teamed up to publish a report on the importance of preserving access to Medicaid coverage for children and youth with special health care needs. In 2017, as Medicaid was once again under attack during the debate over the repeal of the Affordable Care Act, CCF and members of the Family Voices network produced a series of videos to focus on the children and families who would be harmed if proposals to cap and cut Medicaid were approved.

Family Voices is deeply grateful CCF for its timely research, publications, and other products that support the work of child-health advocates around the country. The expert CCF staff provide critical, useable information in many formats - from easy-to-understand blog posts to in-depth data analyses. They share their work and wisdom with partners at the state and federal levels, and facilitate coalition-building among advocates. *Thank you for being an invaluable resource to Family Voices and other advocates working toward a day when all children have access to the care they need at a price their families can afford.*

WELCOME TO THE NEW F2Fs

It is a great honor to welcome eight new Family-to-Family Health Information Centers to the Family Voices Network. We know they each bring extraordinary insight on the needs of families of children with special needs in their communities and that each group is working extremely hard in their first planning year to assess needs, meet with important partners, and evaluate how best to serve families of children with special needs in their communities, based on their assets.

Family Voices staff have had the great privilege to visit each of the five territories in this start-up year and has been greatly impressed by the dedication and energy with which these groups are beginning.

Congratulations to American Samoan F2F, Commonwealth of the Northern Mariana Islands (CNMI) F2F, Guam F2F, Navajo Family Voices F2F, Project CARES (Cultivating American Indian Resource Expansion in the Southwest) F2F, Puerto Rico F2F, Stone Soup Group Alaskan Native F2F, and the U.S. Virgin Islands F2F.

Each group is working to set up peer-to-peer connections, support, resources, and training for parents, family members, providers, and communities to better support children and youth with special health care needs and their families. Navajo Nation has described a goal that resonates across our diverse national network - a goal to establish a holistic information and support system incorporating Diné cultural practices and principles in planning and decision-making for wellness and success. *Áłchíní hózhóójí bá Nabał'á* means "planning for the children in a blessing manner." We look forward to learning much from and sharing much with these vibrant new members of our network.

We'd like to introduce the following representatives from each of the new F2Fs:

American Samoa F2F

Izu Eliapo
Nino Unutoa

***Commonwealth of Northern
Mariana Islands (CNMI) F2F***

Danielle Su

Guam F2F

Gloria Camacho

***Navajo Family Voices F2F at
Indian Country Grassroots***

Josey Foo
Beverly Maxwell
Elvira Dennison
Hazel James

***Project CARES F2F at the
Arizona and New Mexico F2Fs***

Naomi Sandweiss
Christopher Tiffany

Puerto Rico F2F

Giannina Lopez

***Alaskan Native F2F at
Stone Soup Group***

Alexandra Fogarty
Mary Middleton

US Virgin Islands F2F

Jacquiline Thomas
Vienna Khodra
Mabel Maduro
Yvonne Petersen

Special Guests

Honorable Senator Oakland Benta, US Virgin Islands
Roseani Sánchez, APNI in Puerto Rico, FVAO



CARRYING THE VISION

The Family Voices Board of Directors

Our Board of Directors is the foundation of the Family Voices organization. Our Directors are passionate advocates dedicated to ensuring quality healthcare for all children, especially children with special health care needs. They understand the importance of family engagement at all levels of health care, and they generously donate their time and expertise. We are grateful for their wise counsel, candor, and sound judgement which help Family Voices to keep families at the center of children's health care.

Current Directors

Julie Beckett
Iowa

Merrill Friedman
Virginia

Deborah Klein Walker
Massachusetts

Dennis Kuo
New York

Sharon Lewis
Virginia

Nanfi Lubogo
Connecticut

Jill McCormick
Washington

Aimee Ossman
Virginia

James M. Perrin
Massachusetts

Tom Rose
Colorado

Peters D. Willson
New Jersey



FAMILY VOICES STAFF AND CONSULTANTS

Staff

Nora Wells
Bev Baker
Cara Coleman
Beth Dworetzky
Lorena Esparza
Maria Isabel Frangenberg
Janis Guerney
Clarissa Hoover
Ashlee Richey
Will Simpson
Trish Thomas
Melissa Vickers
Allysa Ware

Consultants

Carolyn Allshouse
Betsy Anderson
Diana Autin
Ayo Bajomo
Heather Bowie
Beth DeHoff
Carolyn Fisher
Glenn Gabbard
Liz Healey
Mary Jo Paladino
Mercedes Rosa
Matthew Shapiro
Luisa Soaterna



DEDICATION

This event is dedicated to our children, youth and families who strive every day for affordable, accessible, and quality health care.

Our Children and Youth

Our children and youth with special health care needs are, above all, children and youth who deserve a healthy, happy childhood and a chance to grow up to be productive adults. Like all children and youth, they live with their families in towns, cities, and rural areas of the United States, going to school, attending worship services, enjoying community events. However, unlike most children and youth, they also have challenging health conditions that usually make their lives and their families' lives more complicated. Some of our children and youth have physical, mental, or emotional disabilities; others live with a chronic illness; many have a brief but life-threatening medical problem. Any child or youth, at any time, could develop a disability or chronic health condition.

Our Families

We all come from families. Families come in all sizes, compositions, and configurations. They may be big, small, extended, nuclear, multi-generational, or of some other variety. We live under one roof or many. A family can be as temporary as a few weeks or as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. As family members, we nurture, protect, and influence one another. Families are dynamic and have cultures unto themselves, with different values and unique ways of realizing dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Each family has strengths and qualities that flow from individual members and from the family as a unit. Our families create neighborhoods, communities, states, and nations.

(From the New Mexico Children's Continuum and New Mexico Advocates for Children and Families, 1990)

Family Voices Thanks our Sponsors

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FOR CHILDREN'S HEALTH*

*CHILD AND ADOLESCENT HEALTH
MEASUREMENT INITIATIVE (CAHMI)*

AMERICAN BOARD OF PEDIATRICS FOUNDATION



OUR NATIONAL NETWORK OF FAMILY ORGANIZATIONS

At the core of Family Voices are grassroots families supported by MCHB-funded Family-to-Family Health Information Centers (F2Fs) and Family Voices Affiliate Organizations (FVAOs). These family organizations provide critical support to families caring for children and youth with special health care needs (CYSHCN), including families of children with complex needs and those from diverse communities. F2Fs and FVAOs also work at state, regional, and national levels to improve systems and policies that affect children and families, and they prepare and support new and diverse families of CYSHCN to participate in systems change.

■ Both F2F & FVAO
 ■ FVAO ONLY
 ■ F2F ONLY

AK Stone Soup Group	MA Massachusetts Family Voices @ the Federation for Children with Special Needs	NY Family Voices New York @ Parent to Parent of NYS
AK Alaska Native/American Indian Family to Family @ Stone Soup Group**	MD The Parents' Place of Maryland	OH Ohio Family-to-Family Health Information Center
AL Family Voices of Alabama	ME Maine Parent Federation	OK Oklahoma Family Network, Inc.
AS American Samoa Department of Health*	MI Michigan Family Voices @ The Arc of Michigan	OR Oregon Health and Science University
AR Arkansas Disability Coalition	MI Michigan Public Health Institute	PA Parent Education & Advocacy Leadership (PEAL) Center
AZ Raising Special Kids	MN Family Voices of Minnesota	PR University of Puerto Rico Medical Sciences Campus*
AZ Indian Country Grassroots**	MN PACER Center, Inc.	RI Rhode Island Parent Information Network (RIPIN)
CA Family Voices of CA @ Support for Families of Children with Disabilities	MO University of Missouri Kansas City Developmental Disabilities Resource Center	SC Family Connection of South Carolina, Inc.
CO CBR YouthConnect	MP Northern Mariana Islands Commonwealth Healthcare*	SD South Dakota Parent Connection, Inc.
CT PATH Parent to Parent / Family Voices of Connecticut	MS Family Voices of Mississippi, University of Southern Mississippi	TN Tennessee Disability Coalition
DC Advocates for Justice and Education	MT Parents Let's Unite for Kids (F2F until 5/31/19)	TX Texas Parent to Parent
DE Delaware Family Voices, Inc.	MT University of Montana (beginning 6/1/19)	UT Utah Family Voices Health Information Center
FL Family Network on Disabilities of Florida, Inc	NC Exceptional Children's Assistance Center (ECAC)	VA Family to Family Network of Virginia - Center for Family Involvement @ VCU
GA Parent to Parent of Georgia	NC Family Resource Center South Atlantic	VI Virgin Islands Developmental Disabilities Council, Inc.*
GU Guam Department of Public Health & Social Services*	ND Family Voices of North Dakota, Inc.	VT Vermont Family Network
HI Hilo'pa'a Family-to-Family Health Information Center	NE PTI Nebraska	WA Washington PAVE
IA Family Voices of Iowa @ ASK Resource Center	NH New Hampshire Family Voices	WI Family Voices of Wisconsin, Inc.
ID Idaho Parents Unlimited, Inc.	NJ Statewide Parent Advocacy Network (SPAN)	WV West Virginia University's Center for Excellence in Disabilities
IL Family Voices of Illinois/ The Arc of Illinois	NM Parents Reaching Out (PRO)	WV West Virginia Parent Training and Information (WVPTI)
IN Family Voices Indiana	NM Parents Reaching Out/ Raising Special Kids (AZ)**	WY UPLIFT - WY Family Voices
KS Families Together, Inc.	NV Family TIES of Nevada	WY Wyoming Institute for Disabilities (WIND)
KY Family Voices of KY/KY Family-to-Family Health Information Center		
LA Bayou Land Families Helping Families		

*new F2F in U.S. Territory **new F2F serving tribal nations



**WORKING TOGETHER TO
ADVANCE CHILDREN'S
HEALTH CARE**

 CHILDREN'S
HOSPITAL
ASSOCIATION
childrenshospitals.org

FAMILY VOICES®
... keeping families at the center of children's health care

**SPEAK NOW
FOR KIDS**

The American Academy of Pediatrics recognizes that perspectives and information provided by **families, children, adolescents, and young adults** are essential components of collaborative decision-making in the delivery of high-quality, safe, and compassionate health care.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®



Our thanks to Senator Chuck Grassley for making it possible for Family Voices to hold this reception in Room 902 of the Hart Senate Office Building.

Family Voices ♥ www.familyvoices.org ♥ 888-835-5669