

2012 HEALTH SUMMIT HIGHLIGHTS



The voice of families

The vision of quality health care

The future for children and youth with special health care needs

2012 HEALTH SUMMIT AND LEGISLATION DAY

Family Voices of California (FVCA) is a statewide collaborative of locally-based parent-run centers working to ensure quality health care for children and youth with special health care needs. On March 13-14, 2012, FVCA held its tenth annual statewide Health Summit in Sacramento, bringing together families, advocates, state agency representatives, health policy advocates, legislative representatives, providers and insurers. The Summit focused on identifying budget issues in California that significantly affect the health care of special needs children and developing strategies to ensure that families in California are able to access family-centered, affordable care.

The 2012 Health Summit was held at the Sacramento Convention Center for the location, amenities offered and availability. Through the support of several generous sponsors, Family Voices provided translated materials, a Spanish interpreter, breakfast and lunch as well as childcare for the children of attending families.

Included on the agenda, were many knowledgeable and 'Budget savvy' speakers, including California Senators Mark DeSaulnier and Mark Leno. The Summit moderator, Rocio Smith, encouraged questions and dialogue between speakers and audience members. A panel of speakers addressed proposed budget amendments from national, state and local perspectives. After the Budget overview, moderated by Laurie Soman, the panel answered many questions, followed by lively breakout sessions for group discussion. Additional speakers targeted proposed Budget items, expanding and reinforcing previous content. Fortunately, the day's wrap-up was a 'What's Next' presentation by Dr. David Alexander who had generously agreed to speak again this year.

Summit evaluations indicated that the Summit fulfilled attendee expectations, including being better informed and more prepared for the following day's meetings with legislators.

Surprisingly, after a long day, more than fifty family members and Family Resource Center staff energetically met for a family dinner at a restaurant next to the Holiday Inn, Capitol Plaza.

The venue allowed for lively discussion and an opportunity for families to get to know one another.

This year's Health Summit proved to be a great success with a total of 92 participants, including 60 families, 32 professionals. Seventeen counties were represented, ranging from as far north as Humboldt and Shasta Counties to Sand Diego in the south.

On March 14, Legislation Day, 35 participants gathered at the State Capitol to learn how to impact legislation that would provide access to quality, affordable health care for special needs children and youth. The day began with a brief speech by Erin Auberg-Givens of the Children's Specialty Care Coalition. Participants met with nearly 22 legislators to discuss policy issues and exchanged information to continue the dialogue beyond the Summit.

In an evaluation of the Summit, participants overwhelming responded that the conference enabled them to take action and address policy issues affecting children with special health care needs. One parent interviewed said his biggest take away from the two days in Sacramento was Commitment. His final comment in a thank you letter to his legislator stated his reason for being an advocate for his child: ".....we are firmly convinced that the ongoing services and programs in the State of California for this population have made, and will continue to make, a huge difference in the life and future of our children and their families. And it is this noble purpose that keeps our voices together as we encourage the consideration of our legislators in favor of the needs of those very special children whose ways in life -as different as they may seem- are equally important for the construction of the society we all aspire to live in. " **Aquiles Lopez**

Family Voices of California www.familyvoicesofcsa.org Debbie Brennan Juno Duenas

....I understand that we are faced with hard times in this economy, but I am here with my daughter in hopes to give a voice to other families that are in similar situations and in need of such programs. As stated before these programs are what keep us going, and allow us to be able to function. Please take into consideration my story and my life when you and other state officials are making cuts to these programs." Laura Cruz, parent























DISTINGUISHED SPEAKERS

Family Voices of California was honored to provide a platform for the following presenters who made the Health Summit a success.

March 13, 2012 Presentations

Juno Duenas, Executive Director Support for Families and Council Member, Family Voices of California

Rocio de Mateo Smith, Executive Director Area Board 5 on Developmental Disabilities

Michael Wilkening, Undersecretary of Program and Fiscal Affairs, Health and Human Services Agency

Laurie A. Soman, Senior Policy Analyst, Lucile Packard Children's Hospital

Edwin Park, Senior Fellow, Center for Budget Priorities

Mike Odeh, Associate, Health Policy, Children Now

Scott Graves, Senior Policy Analyst, California **Budget Project**

Eileen Crumm, Executive Director, Family Resource Network

Robert Dimand, M.D., Chief Medical Officer, California Children's Services, Department of **Health Care Services**

Senator Mark DeSaulnier, Senate District 7

Anthony Wright, Health Access

Senator Mark Leno, Senate District 3

David Alexander, President and CEO, Lucile Packard Foundation for Children's Health

March 14, 2012 Legislation Day

Erin Aaberg Givans, Executive Director Children's Specialty Care Coalition

10th Annual Health Summit

Learn Together. Support our children's health care needs together.

March 13, 2012

Sacramento Convention Center, Room 202 1400 J Street, Sacramento

8:30 - 9:00 AM	Registration
9:00 - 9:30 AM	Welcome and Overview of Summit
	Juno Duenas, Council member, Family Voices of California and Executive Director, Support for Families of Children with Disabilities
	Moderator: Rocio de Mateo Smith , Executive Director, Area Board 5 on Developmental Disabilities
	Michael Wilkening, Undersecretary of Program and Fiscal Affairs, Health and Human Services Agency
9:30-11:00 AM	Budget Panel Moderator: Laurie A. Soman, Senior Policy Analyst, Lucile Packard Children's Hospital The Federal Budget and what's going on in the Nation? Edwin Park, Senior Fellow, Center for Budget Priorities The Federal Budget with a focus on children's issues Mike Odeh, Associate, Health Policy, Children Now The California Budget; are there additional revenue options? Scott Graves, Senior Policy Analyst, California Budget Project Parent Perspective Eileen Crumm, Executive Director, Family Resource Network
11:00-11:10 AM	Break
11:10-11:30 AM	CCS Pilots, an update Robert Dimand, M.D., Chief Medical Officer, California Children's Services, Department of Health Care Services
11:30-12:15 PM	Break-out Discussion Group All attendees - Small Group Discussion
12:15-12:45 PM	Lunch (pick-up – 2 nd Floor Landing)
12:45-1:15 PM	Current Budget Legislation relative to health care for children with special health care needs Senator Mark DeSaulnier, Representing Senate District 7
1:15-2:00 PM	Affordable Care Act, Essential Benefit Health Package, and how Exchanges may impact families of children with disabilities and special health care needs *Anthony Wright, Executive Director, Health Access*
2:00-2:45 PM	Break-out Discussion Group All Attendees - Small Group Discussion
2:45 -3:30 PM	Trigger cuts, Managed Care, Medi-Cal and Healthy Families Laurie A. Soman, Senior Policy Analyst, Lucile Packard Children's Hospital
3:30 -4:00 PM	Large Group Discussion All attendees
4:00 -4:25 PM	Budget outlook relative to health care for children with special health care needs Senator Mark Leno, Representing Senate District 3
4:25 -4:45 PM	What's next? David Alexander, President and CEO, Lucile Packard Foundation for Children's Health
4:45-5:00 PM	Evaluation
4:50-5:00 PM	Closing Remarks & Legislative Day Information

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