The voice of families
The vision of quality health care
The future for children and youth with special health care needs
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 San 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 overwhelmingly 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

- **Mike Odeh**, Associate, Health Policy, Children Now

- **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 – 2nd 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
Thank You To Our 2012 Sponsors: