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 8 locally-based parent-run centers working to ensure quality health care for children and youth with special health care needs. On February 25, 2013, FVCA held its 11th annual statewide Health Summit in Sacramento, bringing together families, advocates, state agency representatives, health policy advocates, legislative representatives, providers and insurers. Long before the event the FVCA 2013 Summit Advisory Committee, made up of families and professionals (see page 8 for the list) worked together to create the day.

The vision for the 2013 Summit was defined as a world where our children’s health care is self determined, family centered, and quality health care is the norm. The Summit’s objectives included enabling families and providers to learn how budgets and legislation impact access to services, and identifying upcoming ballot initiatives and legislative items to watch. Throughout the Summit, families would have their voices heard regarding the impact of the budget on their children’s health care and related services.

The 2013 Health Summit was held at the Sacramento Convention Center. Through the support of generous sponsors (see page 7), Family Voices of California provided translated materials, a Spanish interpreter, breakfast and lunch as well as caregiving for 14 children of attending families.

This year’s Health Summit proved to be a great success with a total of 103 participants, including 38 parents or adult family members, and 6 youth. They represented diverse areas of the state from Humboldt County in the north to San Diego in the south.

This year’s Summit featured many experts in the field. The Summit moderator, Catherine Blakemore, Executive Director Disability Rights California set the tone and enhanced the day with thoughtful insights. Jane Ogle, Deputy Director, Health Care Delivery Systems, California Department of Health Care Services, provided an overview of California and was very conscientious about answering all the questions that came her way. Edwin Park, Senior Fellow, Center for Budget Priorities, focused on the federal budget and Scott Graves focused on the California budget. Assembly Member Holly Mitchell gave an insiders look from a legislator’s perspective. Lisa Chan-Sawin of Harbage Consulting provided a clear and concise overview of the Affordable Care Act and Exchange, no easy task. After lunch Kathryn Smith, Associate Director for Administration; USC University Center for Excellence in Developmental Disabilities Children’s Hospital Los Angeles, facilitated a diverse panel of speakers who addressed access to care coverage. They focused on things to celebrate, things to worry about, what to strive for and opportunities for participation.

Every year at the FVCA Summit we take time to have breakout sessions for group discussion. FVCA Council Member Agency representatives guide the conversation with questions: “What did you hear that surprised you?” “What services do you rely on and why are they important to your child?” “What are positive impacts that you heard?” “What are your priority issues and do you have personal stories that demonstrate those concerns?” The purpose of breakout is to help families digest what they

“I want to be a mom — not an insurance cost analyst. However if we are going to be making those decisions then we should be at the table as [policymakers] are making decisions.”

-Parent at FVCA 2013 Health Summit
heard, to reflect on what they have heard, and to write down points they want to discuss with their legislators the following day.

Last, but certainly not least, was a presentation by Dr. David Alexander President and CEO of the Lucile Packard Foundation for Children’s Health titled What’s Next: A Funders Perspective.

Before leaving the summit, participants responded to evaluations and wrote down actions they were going to take once they returned home. They put their lists in self-addressed envelopes, which they will receive within 2 months to remind them of their commitment.

After the Summit, family members and FVCA Council Member Agency staff networked at a family dinner.

On February 26, 43 participants, including parents, their children and youth got up early to meet at the State Capitol for Legislation Day. The day began with presentations from Catherine Blakemore and Evelyn Abouhassan from Disability Rights California, who presented key strategies for meeting with legislators and encouraged participants by reminding them that their voices are important and they deserve to be heard. The participants then fanned out to meet with 40 legislators or their staffs 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 (please see page 6).

“A great step towards becoming a better advocate for my own children as well as other families!”

-Parent at FVCA 2013 Health Summit
Family Voices of California was honored to provide a platform for the following presenters who made the Health Summit a success.

**February 25, 2013 Presentations**

- **Juno Duenas**, Executive Director, Support for Families and Council Member, Family Voices of California
- **Catherine Blakemore**, Executive Director, Disability Rights California
- **Jane Ogle**, Deputy Director, Health Care Delivery Systems, DHCS
- **Edwin Park**, Senior Fellow, Center for Budget Priorities
- **Scott Graves**, Senior Policy Analyst, California Budget Project
- **Assembly Member Holly Mitchell**
- **Lisa Chan-Sawin**, Harbage Consulting
- **Kathryn Smith**, Associate Director for Administration; USC University Center for Excellence in Developmental Disabilities Children’s Hospital Los Angeles
- **Mike Odeh**, Associate, Health Policy, Children Now
- **Mark Edelstein**, Medical Director, EMQ FamiliesFirst
- **Ana Clark**, Manager, State Health Programs, Health Net, Inc;
- **Feda Almaliti**, Parent, Autism Health Insurance Project
- **David Alexander**, President and CEO, Lucile Packard Foundation for Children’s Health

**February 26, 2013 Legislative Day**

- **Catherine Blakemore** Executive Director, Disability Rights California
- **Evelyn Abouhassan** Disability Rights California

---

“Thank you to all who put this info together for families who have kids with disabilities and special needs. I hope more parents realize this exists, so that there will be more voices at the governmental level.”

- Parent at FVCA 2013 Health Summit
11th Annual Health Summit
Learn Together. Support our children’s health care needs together.

March 25th, 2013
Sacramento Convention Center
1400 J Street, Sacramento

AGENDA

8:30 - 9:00 AM Registration

9:00 - 9:15 AM Welcome and Overview of Summit
   Juno Duenas, Family Voices of California Council Member
   Moderator: Catherine Blakemore, Executive Director, Disability Rights California

9:15 – 10:15 AM Overview of California
   Jane Ogle, Deputy Director, Health Care Delivery Systems, DHCS

10:15-11:00 AM Federal and State Overview
   The Federal Budget what’s going on in the nation?
   Edwin Park, Vice President for Health Policy, Center on Budget and Policy Priorities
   The California Budget
   Scott Graves, Senior Policy Analyst, California Budget Project

11:00 - 11:15 AM Break

11:15 -11:30 AM A Legislator’s Perspective
   Assembly Member Holly Mitchell

11:30-12:15 PM Affordable Care Act and Exchange – What are the Specifics?
   Lisa Chan-Sawin, Harbage Consulting

12:15 -12:45 PM Lunch

12:45-2:15 PM Access to Care Coverage: Options for CSHCNs
   Facilitator: Kathryn Smith, Associate Director for Administration USC University Center for Excellence in Developmental Disabilities Children’s Hospital Los Angeles
   Panel: Mike Odeh, Senior Health Policy Associate, Children Now; Mark Edelstein, Medical Director, EMQ FamiliesFirst; Ana Clark, Manager, State Health Programs, Health Net, Inc; Feda Almaliti, Parent, Autism Health Insurance Project

2:15-2:30 PM Break

2:30-3:30 PM Group Discussion

3:30-4:00 PM Report Back

4:00 -4:25 PM What's next?
   David Alexander, President and CEO, Lucille Packard Foundation for Children’s Health

4:25-5:00 PM Closing Remarks & Legislative Day Information Evaluation
**Attendance**

The Summit had **103 participants** this year, with the majority being parents, advocates, or staff of parent centers.

**Evaluation**

In their evaluation surveys, participants identified the ways the Summit impacted them.

- 97% agreed or strongly agreed that the Summit increased their knowledge of services and resources for children and youth with special health care needs.

- 98% agreed or strongly agreed that they learned **new information about policy issues** that affect families of children and youth with special health care needs.

- 91% agreed or strongly agreed that the support/information/resources they received from the Summit helped them feel **more confident about getting their child (or the children they serve) the health care and services they need.**

**Diversity**

*“I was very inspired to see so many people from different backgrounds and life experiences coming together to take action.”*

-Participant at FVCA 2013 Health Summit
Thank You to Our Generous 2013 Sponsors:

Thank You
Family Voices of California 2013 Summit Advisory Committee

Charity Bracy, CA Children’s Hospital Association
Chris Hoene, CA Budget Project
Ed Schor, Lucile Packard Foundation for Children’s Health
Elisabeth Hoy, Patient and Family Centered Care Partners
Janice Milligan, HealthNet
Janice Connallon, Lucile Packard Foundation for Children’s Health
Kathryn Smith, University of Southern CA; University Center for Excellence in Developmental Disabilities at Children’s Hospital Los Angeles
Laurie Soman, CRISS Project, Lucile Packard Children’s Hospital
Mike Odeh, Children Now
Mark Polit, State Council on Developmental Disabilities
Tony Anderson, The Arc of CA
FVCA COUNCIL MEMBERS

San Francisco County
Coordinating Office: Support for Families
2601 Mission Street, Suite #606
San Francisco, CA 94110
Phone: 415.282.7494 Fax: 415.282.1226
Email: pmarks@familyvoicesofca.org
Contact: Pip Marks

Santa Barbara County
Alpha Resource Center, Family First Program
4501 Cathedral Oaks Road
Santa Barbara, CA 93110
Phone: 805.683.2145 Fax: 805.967.3647
Email: info@alpharesourcecenter.org
Contact: Patty Moore

San Diego, Imperial County
Exceptional Family Resource Center
9245 Sky Park Court, Suite #130
San Diego, CA 92123
Phone: 619.594-7416 Fax 858.268.4275
Toll Free: 800-281-8252
Email: efrc@projects.sdsu.edu
Contact: Sherry Torok

Fresno, Kings County
EPU Children’s Center
4440 North First Street
Fresno, CA 93726
559.229.2000 x193 Fax: 559.229.2956
Website:www.epuchildren.org
Email: krose@epuchildren.org
Contact: Krista Rose

Butte, Glenn, Shasta, Siskiyou, Tehama and Trinity Counties
Rowell Family Empowerment of Northern California
962 Maraglia
Redding, CA 96002
Toll Free: 877-227-3471
Local: 530-226-5129
Fax: 530-226-5141
Email: wendy.longwell@rfenc.org
Contact: Wendy Longwell

Los Angeles County
Westside Family Resource and Empowerment Center
5901 Green Valley Circle #320
Culver City, CA 90230-6953
Phone: 310-258-4063; 323-717-7411
Fax: 310 338-9664
Website: www.westsiderc.org
email: family@westsiderc.org
Contact: Linda Joy Landry

Eastern Los Angeles Family Resource Center
1000 South Fremont Avenue
Suite 6050, Unit 35
Alhambra, CA 91803
Phone: 626-300-9171 Fax: 626-300-9164
Website: www.easternlafrc.org
Email: coordinator@elafrc.net
Contact: Yvette Baptiste

Alameda County
Family Resource Network
5232 Claremont Avenue
Oakland, CA 94618
510.547.7322 Fax 510.658.8354
Email: frn@frnoakland.org
Contact: Eileen Crumm