

# FAMILY VOICES of California

## 9<sup>th</sup> Annual Health Summit & Legislative Day

***Moving Forward Together:***

***Let's not lose children and families in this shuffle***

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



# 9<sup>th</sup> Annual Health Summit & Legislative Day

## MARCH 1-2, 2011

Each year, Family Voices of California hosts a statewide Summit in Sacramento to bring together families, youth, providers, policymakers, advocates, state agencies, insurers, and other stakeholders to identify and address challenges affecting one of California's most vulnerable populations: children and youth with special health care needs.



## **Family Voices of California is locally based, nationally connected**

**A statewide collaborative of locally-based parent run centers working to ensure quality health care for children and youth with special health care needs. As the State Affiliate of National Family Voices, we are California's federally funded "Family-to-Family-Health-Information-Center" providing statewide support to families of CYSHCN. For more info, visit [www.familyvoicesofca.org](http://www.familyvoicesofca.org)**



# FACES OF THE 2010 SUMMIT



*Emilee Leon and Eileen Crumm*



*Rosa Valledor and Rocio de Mateo Smith*



*Kenneth, Onthya and Nathan Padilla with Senator Mark Leno*



*Francisco Garcia with his daughter*



# HOW MANY CYSHCN IN CALIFORNIA?

- Approximately 15% of all children age 0-17 — about 1 in 6
- Equals an estimated 1.4 million CSHCN living in California

*Christy Bethell / CAHMI / Data Resource Center*



# STORIES OF 2010 SUMMIT:

NITA THOMPSON

Nita described her visits to the State Capital : “The input I was allowed to share was reacted to positively.” She proceeded to visit legislative offices in her area of Los Angeles and worked with Assembly member Anthony J. Portantino to achieve passage of AB52, a bill that proposes an umbilical cord blood collection program for public use. Governor Schwarzenegger signed the bill September 29, 2010! Passage of this bill is monumental in offering hope to those with sickle cell anemia as umbilical cord blood can treat the disease and immune disorders.



*(Left to right) Debra Capers, Assemblymember Anthony J. Portantino and Nita Thompson*



ALL OF THE CSHCN LIVING IN CALIFORNIA  
WOULD FILL 25,454 SCHOOL BUSES AND STRETCH  
174 MILES



How far would the buses span if they were filled with subgroups of California CSHCN?

- Publicly Insured: 49 miles
- Privately Insured: 111 miles
- Uninsured: 14 miles (CA 40<sup>th</sup>)
- White: 83 miles
- Non-white: 91 miles



# STORIES OF 2010 SUMMIT:

LIBBY HOY

“It was not an appealing idea to talk with strangers about our mountain of debt, our low credit rating, and the stream of calls from collection agencies.” But then she thought of the problems within the system and realized the importance of speaking out: “I thought about all the families, like ours, who are living just one medical crisis away from bankruptcy.”

A representative of the American Academy of Pediatrics arranged a conference call between Libby and a group of U.S. Congressional staffers from the Committee on Energy and Commerce. Libby was at first daunted by the call, but Tara Robinson, FVCA’s Manager, coached her on how to address the committee. During the call, Libby spent 20 minutes describing her family’s experience with medical debt. The result? The committee invited her to come to Washington, DC to share her story if a hearing could be arranged.



*(Left to right) Libby Hoy’s sons: Nicholas, 16; Jack, 13; and Stephen, 18*

# HIGHLIGHTS OF CSHCN IN CALIFORNIA

How far would the buses span if they were filled with subgroups of California CSHCN?



- Asthma: 73 miles
- 2+ of 16 more common conditions: 103 miles
- CSHCN who are also overweight or obese: 68 miles
- Complex needs: 73 miles
- Functional difficulties: 152

*Christy Bethell / CAHMI / Data Resource Center*



# STORIES OF 2010 SUMMIT:

## KEVIN-DAT VU

- At the 2010 Health Summit, Kevin learned how proposed budget cuts to health care could affect him and his community, fueling his fire to advocate for disabled youth. “As much news as I watch, I have a better grasp of the state and federal budget because of the Health Summit.”

From FVCA’s budget analysis, Kevin could see the gravity of the reductions at a glance: “I calculated the total of the trigger cuts and overall cuts, and it was \$7 billion, \$936 million. Those numbers are about me. Just to see that opened my eyes in a big way.” The Health Summit armed Kevin with knowledge that has given him more leverage and confidence when speaking with legislators, including Insurance Commissioner Mike Villines and a representative of Senator Thad Cochran, cosponsor of the Blind Persons Return to Work Act.



*Kevin-Dat Vu joins other advocates at the State Capitol*



## IN PERSPECTIVE

573,000 CSHCN in CA have asthma,  
which is the equivalent of enough  
children to fill 30 Staples Centers!

- 29 for CSHCN with 2+ conditions
- 20 for CSHCN with emotional,  
developmental or behavioral health  
issues
- 17 for ADHD
- 3.35 for Autism/ASD
- 1.88 for Cerebral Palsy
- 1.52 for Epilepsy
- .78 for Diabetes
- .57 for Down Syndrome



Christy Bethell/CAHMI/Data Resource Center



# STORIES OF 2010 SUMMIT:

## THE PADILLAS

- On Legislative Day, the Padillas visited to the State Capitol to meet with State Senator Mark Leno: “Mark Leno gave us time, seemed genuinely interested, and inquired about my son's disability. Our story matters, especially when shared with legislators.”

The Padillas walked away with newfound confidence and insight. With regard to state agencies, Kenneth Padilla says, “I've been better willing to work with them because . . . I know more laws. The result has been positive and has made us grow.” When state agency representatives ask how he has been well informed, Kenneth tells them about the Summit's Legislation Day. This, he explains, has opened many doors to an often closed system.



*Kenneth, Cynthia and Nathan Padilla with Senator Mark Leno*



# HEALTH INSURANCE

**Gaps in coverage:** Nearly one in five CSHCN is uninsured for at least part of the year

*Christy Bethell / CAHMI / Data Resource Center*



## NATIONAL COMPARISON

California rates in the bottom third of all states on all 11 Quality of Care Measures, with 10 Quality Measures falling in the bottom 8 states

- Ranked 46<sup>th</sup> in nation for inadequate insurance
- Ranked 48<sup>th</sup> in nation for care coordination
- Ranked 45<sup>th</sup> in nation for developmental screening
- Ranked 45<sup>th</sup> in nation for transition to adulthood
- Ranked 43<sup>rd</sup> in receiving needed mental health services

*Christy Bethell / CAHMI / Data Resource Center*

## NATIONAL COMPARISON

California rated worst state in nation for:

- Having at least one preventive care/well visit
- Meeting baseline criteria for having a Medical Home
- Receiving family-centered care
- Usual source of sick and well care
- Above average stress among parents of CSHCN
- Quality Index (18% met minimal index for adequate insurance, preventive care visit and medical home)

*Christy Bethell / CAHMI / Data Resource Center*

## IMPACT ON FAMILIES

- Families spend 3,780,000 hours per week coordinating their child's care, which is equivalent to 94,500 full-time employees in CA
- 330,000 families cut back or stopped working to care for CSHCN—almost 3X the size of Humboldt County

*Christy Bethell / CAHMI / Data Resource Center*

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