

California Coalition for Child Health Research

California Coalition for Child Health Research

- Create a collaboration between academic researchers and health advocates throughout California
- Utilize overlap between advocacy group and academic institutions
- Support research that directly translates to improving children's health in California
- Generate data to inform policy decisions

California Coalition for Child Health Research

- CHLA
- Harbor-UCLA
- Loma Linda University
- Rady Children's Hospital
- Stanford University
- UCI
- UCSD
- Valley Children's Hospital

Children's Specialty Care Coalition

- Established in 1999 to address availability of pediatric specialty care in California
- Represent pediatric subspecialists
- Advocacy through interactions with state legislature, state agencies pediatric organizations
- Representation on:
 - DHCS Advisory Board
 - Medi-Cal Access Committee
 - CCS Advisory Council
 - California Telehealth Policy Coalition
 - Medical Loan Repayment Program



CSCC Membership

- California Association of Neonatologists
- Rady Children's Specialists of San Diego
- Shriners Hospitals for Children
- The Children's Center at Sutter Medical Center
- Children First Medical Group UCSF Benioff Children's Hospital Oakland
- UCSF Department of Pediatrics, Benioff Children's Hospital San Francisco
- Childnet/Specialists Medical Group, Valley Children's Hospital, Madera
- Cottage Children's Medical Center, Santa Barbara
- Community Regional Medical Center, Fresno
- Mattel Children's Hospital, David Geffen School of Medicine at UCLA
- Stanford University Department of Pediatrics
- UCD Department of Pediatrics
- Department of Pediatrics, Loma Linda University Faculty Medical Group, Inc.
- UCI Department of Pediatrics
- Children's Hospital of Orange County
- Miller Children's Subspecialty Group, Long Beach
- Children's First Medical Group, Oakland
- California Pacific Medical Center
- Children's Hospital Los Angeles Medical Group

CSCC Membership

- 2,500 + pediatric subspecialists
- Represent approximately two-thirds of Pediatric specialists in California

Coalition's Mission

- Ensure that children with complex health care needs have access to timely and high quality medical care
- Ensure that pediatric pediatric specialists are able to thrive in California's health care environment through strong leadership, education and advocacy

Coalition Activities

- Advocacy
- Education
- Research
- Best practices

The Need for Advocacy

- 1 in 25 children in the US are considered medically complex
- Rate of medically complex children is expected to double within the next decade
- Medically complex children require by more than one pediatric specialists and access beyond medical system
- 34% of California families with children with special healthcare needs reported difficulty accessing care

The Chartis Group White Paper, Advancing Care Models for Children with Complex Health Care Needs

Bethell C, et al. Children with Special Health Care Needs in California: a profile of key issues

Barriers to Access

- Medi-Cal rates are still not sufficient to recruit and retain providers for certain subspecialties
- Physicians are opting to work in other states where the cost of living is lower and reimbursement/salaries are higher
- More medical students are opting for general or hospitalist track due to post graduate debt, and amount of time and cost in lost salary to become a pediatric subspecialist, while the current workforce is aging and approaching retirement.

Barriers to Access

- Most children's hospitals are concentrated in more densely populated areas
- Uneven distribution of pediatric subspecialty care

CSCC Advocacy Goals: 2018-2019

- Advocate for sufficient Medi-Cal reimbursement to maintain access to specialty care for children
- Support care for medically complex children with benefit of improving care for all children
- Increase funding for medical school debt reduction/loan forgiveness to encourage medical students to pursue pediatric subspecialties
- Increase funding to support an expansion of telehealth and e-consult services.



California Coalition for Child Health

Research: Purpose

- Catalyze and incubate research focused on the health needs of California's children.
- Provide needed data to improve child health across the the state.
- Build teams and generate data that will be used for subsequent grant applications.

Child Health Research: Eligible Projects

- Active or planned collaboration between CCCHR sites.
- Clear anticipated benefits for pediatric research and child health.
- Utilize data, expertise and resources from CCCHR sites

Examples of Projects

- Impact of regional environmental factors on childhood diseases.
- Best practices for Neonatal Opioid Withdrawal.
- Impact of regional healthcare/access to care on disease outcomes in child health.

CCCHR Submissions

- Split Genome Gene Therapy Approach for Treatment of SCN1A-related Epilepsies
- Harnessing Collaboration across California to Standardize Pediatric Pain Management and Reduce Pediatric Opioid Exposure
- Cost-effectiveness of Early Whole Exome Sequencing to Improve Neonatal Health Outcomes
- The Prevalence of and Practices Regarding Cancer Predisposition Syndromes in Pediatric Academic Medical Centers in California



CCCHR

- Initial project chosen following external, independent review
- Investigator meeting scheduled
- Managing success of initial project
 - Engaging sites
 - Distribution of funds
 - Adherence to timeline
- Supporting ongoing collaborations