

# **EPILEPSY STATE FORUM**

## *Improving Access to Care for Children and Youth with Epilepsy in California*

February 25, 2008  
Sacramento, CA

*Presented by:*

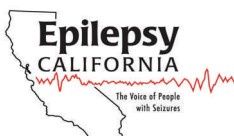
*Epilepsy California*

*Epilepsy Foundation of Northern California*

*Epilepsy Foundation of Greater Los Angeles*

*Epilepsy Foundation San Diego County*

*University of Southern California, University Center for  
Excellence in Developmental Disabilities, Childrens  
Hospital Los Angeles*



# Forum Purpose

Over the past three years the University of Southern California's University Center for Excellence in Developmental Disabilities at Childrens Hospital Los Angeles has been working to improve access to services for children and youth with epilepsy in our state in partnership with the three Epilepsy Foundation affiliates in California. We have uncovered many barriers encountered by families and professionals in providing optimum care. We have collected data to define access issues through a survey of physicians, community-based meetings, conversations with California Children's Services, Regional Centers, Schools, Pediatric Neurologists, Pediatric Neurology Clinics and meetings/correspondence with many other organizations and individuals. Based on the information we gathered, the most important issues can be broadly categorized as 1) children's health issues, 2) epilepsy barriers within schools, 3) women's health concerns and 4) the shortage of pediatric neurology specialists in California. In order to further explore and define the barriers and challenges in these four areas, and to identify strategies to overcome them, the UCEDD and the Epilepsy Foundation affiliates brought together agencies and programs serving children with epilepsy, healthcare and education professionals, families, and policy-makers at a forum in Sacramento on February 25, 2008. Forum participants developed a consensus on the issues, and begin to define what action can be taken to alleviate or reduce the barriers to care that children with Epilepsy and their families encounter in CA. These data will then provide policymakers with a clear agenda of issues, as well as recommendations that must be implemented to assure the highest possible quality of life for children with epilepsy in CA. This document, assembled by the USC UCEDD, CHLA and the three Epilepsy Foundation affiliates in California, also known as Epilepsy California, includes an overview of each of the four focus areas and concludes with the suggestions and recommendations the participants developed as a result of this forum.

# About the Forum Participants

The Forum participants include and/or represent the following organizations:

Epilepsy California	Family Voices of California
Epilepsy Foundation of Northern California	Family Resource Center Network of California
Epilepsy Foundation of Greater Los Angeles	California Regional Centers
Epilepsy Foundation of San Diego County	California School Nurses Organization
USC University Center for Excellence in Developmental Disabilities, Childrens Hospital Los Angeles	Epilepsy Support Groups
David Geffen School of Medicine, University of California, Los Angeles	Managed Care Organizations
Los Angeles County/University of Southern California Medical Center, Women's and Children's Hospital	Public Health Departments
Children's Hospital of Orange County	California School Districts
California Children's Medical Services, California Children's Services	County Offices of Education
Department of Developmental Services	Neurologists
	Sutter Neuroscience Institute, Sacramento
	Alameda County Children's Special Needs Committee
	California Children's Regional Integrated Services System (CRISS)

## **Children's Health Care**

Epilepsy is the most prevalent childhood neurological disorder and yet barriers to primary healthcare still exist, including mobility and sensory impairment, behavior problems, difficulties with communication, inadequate knowledge and attitudes of staff, reduced access to specialty care, and lack of time and resources. Other issues include navigating through managed care systems without a proper medical home or care coordination, brand medications being switched to generic or changed from one generic to another resulting in potential compromising of the delicate balance in seizure control, and the lack of coordination for transitioning adolescents to adult providers. Children with epilepsy also may have co-morbidities including, but not limited to, autism, attention-deficit/hyperactivity disorder, depression, and learning disabilities, which are not being screened for properly. Difficulty in accessing mental health services is also an important area of concern. Listed below are some of the important issues we have discussed, along with recommendations for improvement as identified by the Children's Health Care workgroup at the Epilepsy State Forum.

### 1. Issues: Best Practices for Providers

#### Recommendations:

- Develop a quality of care standard for children with epilepsy that are seen by primary care physicians to ensure consistent monitoring of all patients.
- Implementation of measures to ensure compliance with the standards of care would further ensure quality of care.
- As part of the expanded California Children's Services and Child Health and Disability Prevention programs, as well as in all standard practice, physicians should use a mental health screening tool for ALL children.

### 2. Issue: Care Coordination

#### Recommendations:

- A standardized process should be developed for physicians to utilize when children are newly-diagnosed with epilepsy to ensure that they know how to navigate the system and advocate for themselves to get services.
- Funding should be provided to other community based programs, such as Family Resource Centers, to provide care coordination for families if physicians' offices cannot.
- Families should be encouraged, guided, and provided the necessary skills to take charge of their child's care.

### 3. Issue: Coverage

#### Recommendations:

- The Family Opportunity Act should be revisited and language specific to California residents included.
- Universal Health Care with a comprehensive benefits package should be implemented in California.
- More funding should be allocated to increase training opportunities and incentives should be offered to those who want to become a pediatric neurologist.
- Reimbursement and benefits packages should be standardized across payers to include coverage for medical homes, care coordination, multidisciplinary teams (CCS Special Care Center model), and mental health screening.

### 4. Issue: Prescription Medication

#### Recommendations:

- Patient, Physician, and Pharmacist education should be expanded to prevent drug switching between anti-epileptic drugs without the consent of the patient and/or the child's family and the physician treating the child.
- Pharmacies should provide families with more information about the potential side-effects of the medications prescribed for children.

# Shortage of Pediatric Neurologists

There is a shortage of pediatric neurologists in California. Factors which contribute to this shortage are inability to recruit and retain physicians, decreasing enrollment in training programs for pediatric neurologists, regulatory constraints, low reimbursement and increased referrals, constraints due to managed care systems, as well as medical liability concerns affecting all physicians. Related problems resulting from the shortage of pediatric neurologists include poor communication between the primary care provider and the specialists, and parents not receiving the level of education they require to fully understand the child's condition. Dissatisfaction is high amongst physicians because of regulatory requirements which create delay in, and inefficiency of, care for children with epilepsy. Inability to be compensated adequately for treating children with complex needs related to epilepsy adds to discontent, as well as excess demands on neurologists because there are no clear guidelines or service agreements. Listed below are some of the important issues we have discussed along with recommendations for improvement identified by the Shortage of Pediatric Neurologists workgroup at the Epilepsy State Forum.

## 1. Issue: Recruitment and Retention

### Recommendations:

- Pediatric neurologists should be encouraged to outreach to pre-medical and medical students and promote the specialty.
- CCS special care centers should be created for epilepsy to provide support to physicians and patients by incorporating a multi-disciplinary team for patient visits.
- Expand the public health service tuition remission program to specialists, specifically pediatric neurologists, and add the provision that work would need to be done in California after matriculation.
- Regulating managed care systems and settling reimbursement issues would alleviate unnecessary stress for both physicians and patients.
- By eliminating the 10% budget cut and restoring reimbursement rates to the Medi-Cal and CCS programs neurologists could be better compensated and more willing to see Medi-Cal patients.
- Increased referrals to pediatric neurologists

## 2. Issue: Decreased enrollment in training programs

### Recommendations:

- Encourage medical students to apply for pediatric neurology specialty by expanding the public health service tuition remission program for specialists.
- For those studying medicine or applying to residency programs in California, should have a provision that they will work in California after matriculation for at least a few years, should be included if they receive tuition remission.

## 3. Issue: Managed care, regulatory and reimbursement issues

### Recommendations:

- Regulating managed care systems and settling reimbursement issues would alleviate unnecessary stress for both physicians and patients.
- By eliminating the 10% budget cut and restoring reimbursement rates to the Medi-Cal and CCS programs, neurologists could be better compensated and more willing to see Medi-Cal patients.

## 4. Issue: Increased referrals to pediatric neurologists

### Recommendations:

- Increase continuing medical education opportunities to primary care physicians to empower them with a level of comfort in initiating patient management.

# Epilepsy in the School

Students with epilepsy and their families face unique challenges and present with special needs across all educational settings. Fortunately, there is, a parent support pathway to enable them to become advocate partners with educators to address education related concerns. School Personnel and parents face a variety of challenges. Common concerns include the administration of medicines, consistent access to seizure rescue medicines, and learning disabilities that sometime are overlooked. There are laws protecting students with epilepsy and seizure disorders so that they can attend school in the least restrictive environment possible. Listed below are some of the important issues we have discussed along with recommendations for improvement identified by the Epilepsy in the School workgroup at the Epilepsy State Forum.

## 1. Issue: Education and Awareness

### Recommendations:

- Epilepsy Foundation programs should be offered to schools more frequently.
- All materials should be available in Spanish and other languages if possible.
- Epilepsy Foundation materials should be available for free or at reduced cost to schools and organization.
- Education handbooks should be provided to parents as they advocate for their children.
- Health classes for students should discuss epilepsy to educate children and youth.
- IEP/Section 504 trainings should be offered regularly for parents.
- Classmates and teachers should be educated about epilepsy/seizure disorder, medications, etc.
- Kids should have a seizure action plan developed by the physicians, and if he/she has an IEP/504 Plan, the action plan should be included as part of the plan
- Parents should be trained to maneuver through the education system.

## 2. Issue: Emergency Medication for Students

### Recommendations:

- Legislation should be developed that allows students to have access to seizure rescue medications similar to kids having access to Epi-Pens and insulin.
- Uniform, mandatory regulations should be in place within schools regarding dispensation of medications in schools
- California School Nurses Organization and board of nursing should provide support and guidelines in partnership with the Epilepsy Foundation to determine who can administer medication during school hours.

## 3. Issue: Collaboration between Epilepsy Foundation

### Recommendations:

- Legislation should be passed that states that a licensed nurse be at all schools with a ratio of 1 to 750 students.
- Community leaders and caregivers should have open discussion opportunities about defining the needs and establishing directions for children with epilepsy/seizure disorder.
- Issues should be continuously revisited during annual California School Nurses Organization Conference.
- A Web page should be established for discussion and posting resources open to the public.
- Schools should better monitor bullying around the campus and offer more mental health services.

## 4. Issue: Awareness, utilization and retention of existing policies/ resources

### Recommendations:

- Eligibility criteria for services and systems should be better defined.
- Legal rights pamphlet should be developed outlining everyone's rights and how to advocate for them.
- Other avenues for dissemination and education should be explored including telecommunication and technological resources.

## Women's Health Care

There are many issues affecting women with epilepsy and in particular adolescent women with epilepsy. Studies have shown that the stigma associated with epilepsy can be overcome through educational programs within schools starting at an early age. While it is important to educate the general population, there are few specialists who focus on the care of women with epilepsy. Therefore, many general physicians (pediatricians, internal medicine doctors and gynecologists) need to be educated about the special issues related to this population. Socially, women with epilepsy have a lower marriage and reproductive rate. Moreover, unique issues include: sexual dysfunction, catamenial epilepsy, bone health and birth control. Lastly, there is a higher prevalence of psychiatric disorders (depression, anxiety, suicide) in individuals with epilepsy making access to good psychiatric care essential. Listed below are some of the important issues we have discussed along with recommendations for improvement identified by the Women's Health Care workgroup at the Epilepsy State Forum.

### 1. Issue: Stigma & Public Awareness

#### Recommendations:

- Increasing educational materials and tools that are distributed through the Department of Public Health can help raise awareness about epilepsy thus decreasing stigma.
- Increasing school-wide educational opportunities helps children and youth become more tolerant of classmates with special health care needs.
- Public Awareness Television Campaigns allow for a wider audience to become educated about health concerns.
- Increasing Wellness Grants through the Department of Developmental Services allows for more opportunities for increasing public awareness.

### 2. Issue: Screening, Diagnosis, and Appropriate Care

#### Recommendations:

- Developing a referral form for physicians to have available in their office allows newly diagnosed women to coordinate their care and be aware of what steps they need to take.
- Issuing standards of care allows for a consistent protocol for care coordination to ensure quality health care services.
- Electronic medical records allow for streamlined communication between physicians to maintain continuity of care.
- Development of Screening tools for different types of seizures allows for proper diagnosis.
- Development of Screening tools for mental health enables physicians to discover comorbid conditions.
- Allowing Medi-Cal and health insurance companies to reimburse all members of interdisciplinary teams promotes collaboration and provides comprehensive health care.

### 3. Issue: Educating Physicians

#### Recommendations:

- Increase continuing medical education opportunities to educate primary care providers about issues related to women with epilepsy.
- Better communication between Specialists and physicians encourages obstetricians and gynecologists to be aware.
- Encouragement of interdisciplinary teams allows for comprehensive health care services for women.
- Information about Drug Interactions readily available in physicians offices allows patients to stay informed.

### 4. Issue: Patient empowerment through education and support

#### Recommendations:

- Having ready and accessible information empowers patients to go out and advocate for themselves.
- Women need mental health support to maintain proper quality of life.
- Increase number of Wellness Grants through Department of Developmental Services to increase opportunities.
- Department of Public Health should develop educational materials about epilepsy to make the information accessible to more people.

## **About Epilepsy California**

Epilepsy California is the recognized, unified voice of people with epilepsy throughout California. Established by the three Epilepsy Foundations in California, Epilepsy California proactively develops a statewide epilepsy agenda and advocates within state government and state agencies for public policies which ensure the rights of people affected by epilepsy to fully participate as contributing members of their communities.

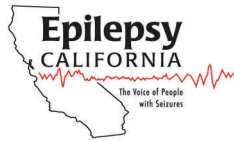
Epilepsy California represents 1 million people in California – those with epilepsy and their family members. One in every 10 Californians will experience a seizure during his or her lifetime. One in 100 Californians will be diagnosed with epilepsy. Every three minutes a new person in America is diagnosed with epilepsy.

Epilepsy is defined as a neurological condition characterized by recurrent seizures and can develop at any stage of life; children and the elderly are particularly affected. Epilepsy can stem from a variety of causes including head trauma, brain tumor, stroke, infection, neurodegenerative disorders including Alzheimer's disease, genetic predisposition, and poisoning. Epilepsy remains a formidable barrier to leading a normal life by affecting employment, education, and every day life.

## **About Project Access**

As the most populous state in the nation, California (CA) is home to more than 9.8 million children. For most of the estimated 85,000 children in CA with a diagnosis of epilepsy (estimated to be 1/6 of children nationally), the goal of eliminating seizures while preventing side effects may be achievable. However, for some children, the barriers in California include the absence of integrated systems of care to uniformly provide services and supports that will ensure the best possible quality of life for children and youth with epilepsy. In April 2004 the Maternal and Child Health Bureau (MCHB), Division of Services for Children with Special Health Care Needs (DSCSHCN) US Department of Health and Human Services (DHHS), Health Resources and Services Administration (HRSA), released a request for proposals soliciting applicants to work toward improving access to comprehensive, coordinated health care and related services for children and youth with epilepsy residing in medically underserved areas (MUAs) and rural areas. The purpose of the initiative, Improving Care for Children and Youth with Epilepsy: Project Access, under Priority Area 1, was for states to develop and implement a plan to improve community-based systems of services for children and youth with special health care needs who have epilepsy and/or a seizure disorder.

The University of Southern California (USC) University Center for Excellence in Developmental Disabilities (UCEDD) at Childrens Hospital Los Angeles (CHLA) was one of eight states that received funding beginning in September 2004. Over the past 3 years the CA Grantee has worked closely in CA with California Children's Services (CCS), the Family Resource Center Network of CA (FRCNCA), three affiliate offices of the National Epilepsy Foundation (Northern CA; Los Angeles, including Orange San Bernardino and Ventura Counties; San Diego County), Pediatric Neurologists, four community-based Medical Home Coalitions and several Pediatric Neurology Programs, affiliated with California Universities and Children's Hospitals.



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