

Friends of Doernbecher Pediatric Epilepsy Monitoring Unit

The Condition

Pediatric epilepsy is a disorder involving repeated seizures of any type. Seizures are episodes of disturbed brain function that cause changes in attention and/or behavior. They are caused by abnormal electrical excitation in the brain. Epilepsy can arise due to congenital problems with brain development, as well as from acquired injuries to the brain, including cerebral palsy, brain infections, brain tumors, and trauma.

Each year in the United States, 45,000 children are diagnosed with epilepsy. Approximately 500 diagnoses are made each year from children under age 18 in Oregon and SW Washington. Many of these children are quickly diagnosed, and respond well to medications which eradicate their seizures. Many of them grow out of their tendency towards seizures after several years, and go on to lead full and normal lives.

Approximately 30%, however, never experience relief from seizures with medications. These children often take multiple medications each day, and experience difficult side-effects which impact their physical and mental wellbeing. Many are restricted in their daily independence due to seizures. Similarly, many experience great social and emotional stigma from a condition which can occur without warning, and cause them to lose control of their bodies. Ongoing, uncontrolled seizures may also injure the body and brain, and lead to regular visits to emergency departments, hospitals, and intensive care units.

The Treatment and Evaluation

Pediatric epilepsy is one of the most serious and common neurological conditions affecting children, and it is often misinterpreted and misdiagnosed by doctors and healthcare providers. Diagnosis is often complicated, and effective treatments vary depending on the physician's ability to establish an accurate diagnosis. Some parents have gone from physician to physician without a clear diagnosis for their child's condition. A correct diagnosis, and access to the full range of treatments, is critical to safe and successful care.

Most children with epilepsy can be treated successfully with medication. Kids receive a thorough evaluation and a series of diagnostic tests which often consist of an electroencephalogram (EEG), specialized MRI studies, and blood tests. When medications are not successful in treating a child with epilepsy, a complex evaluation must be pursued to identify other treatments.

For some children, a focus of seizures may be identified within the brain, and successfully removed with a brain surgery. For others, a vagus nerve stimulator is implanted in the chest, which can help reduce seizures by sending electrical impulses to the brain. With access to these complex diagnostic tests and treatments, many children can become free of seizures; otherwise, they may remain severely debilitated.

The Vision and the Need

The support of the Friends of Doernbecher is being sought to establish a comprehensive Pediatric Epilepsy Monitoring Unit with a dedicated nursing staff specially trained in the care and evaluation of children with seizures. The unit will become the principle home for all pediatric epilepsy patients. Currently, Doernbecher has over 220 annual epilepsy discharges. The Video-EEG equipment used to diagnose seizures, determine optimal medication treatment, and evaluate patients will be modernized to ensure that children from Oregon and Southwest Washington have access to the latest technology, 24 hours a day. As Doernbecher operates the only pediatric surgical epilepsy program in Oregon, having access to state-of-the-art EEG technology will also enhance Doernbecher's recognition as a regional leader that provides surgical interventions to decrease the long term health care needs and enhance the quality of life in children with intractable epilepsy.

Drawn by the expertise of our multidisciplinary team (experts in the fields of pediatric neurology, pediatric neurosurgery, pediatric nursing, neurophysiology, social work, and radiology), families come to us from across Oregon and SW Washington seeking better solutions to their children's problems with epilepsy. Specifically, Doernbecher treats nearly 1,200 children with an epilepsy diagnosis each year, generating over 220 inpatient discharges and 1,075 diagnostic EEGs. A significant number of our patients are referred to us by other pediatric neurologists seeking the best options for their patients. This team has shown early and excellent success in pediatric epilepsy care, from initial diagnosis through complex multi-stage brain surgery.

Because DCH has a reputation for dealing successfully with complex cases, many of our children come to us with seizures that have remained uncontrolled despite multiple medications. These patients and their families require a high-level of medical and social support. Combined with the chronic nature of this condition, the demand for pediatric epilepsy care far exceeds our current ability to provide service. Thus, in order to better meet the needs of children from Oregon and Southwest Washington, it will be necessary to recruit a second pediatric neurologist with a special emphasis in pediatric epilepsy, as well as add to our team of allied support staff.