

the National Pediatric Myoclonus Center (NPMC)

The purpose of a national center for myoclonus is to provide the best care possible for patients whose myoclonus began during childhood. This care includes making the correct diagnosis, searching for all reversible (curable) causes, choosing the best drug treatments available, providing information about myoclonus, obtaining psychological and emotional support for the children and their families, and bringing them together with other similar families. We also wish to establish the scope of the problem and increase awareness among federal, private and pharmaceutical agencies. Patients with myoclonus otherwise have no advocate. They are often misdiagnosed, told there is no hope, feel isolated, and are in need of a concerted effort to better their situation.

History of the Center

The National Pediatric Myoclonus Center (NPMC) was founded in 1985 by Dr. Pranzatelli. In 1990 it became a full service center, largely through the efforts of its first research nurse practitioner Elizabeth D. Tate, FNP, C., MN. The membership consists of patients and their families, health care providers, educators and volunteers who support the mission of the organization. Supported by federal, pharmaceutical, institutional, and private funds, it has grown to be a referral center for the U.S., Canada, Mexico, and other countries.

Michael R. Pranzatelli, M.D., is attending Staff Neurologist and Professor of Neurology and Pediatrics at the Southern Illinois University School of Medicine. A graduate of the Pennsylvania State University in Hershey, Dr. Pranzatelli completed his pediatric residency at Case Western Reserve University in Ohio, and his pediatric neurology training at the University of Colorado. He also completed a three-year research fellowship in neuropharmacology at the University of Southern California's Children's Hospital. He received the prestigious Young Investigator Award of the Child Neurology Society and is certified both by the American Board of Pediatrics and the American Board of Psychiatry and Neurology with special qualification in Child Neurology. Previously, Dr. Pranzatelli was a faculty member at Columbia University in New York City and the George Washington University in Washington, D.C. He has received federal, private and institutional funding for his research on myoclonus, including a Clinical Investigator Development Award from the National Institutes of Health. The Food and Drug Administration Orphan Products Development Program has recently funded his clinical drug trials in myoclonic disorders.

Elizabeth D. Tate, FNP-C., M.N., is a Certified Family Nurse Practitioner at Southern Illinois University School of Medicine. Graduate with distinction of George Mason University School of Nursing, she received her Masters of Nursing from the University of California at Los Angeles. She coordinates research activities, protocols and oversees the pediatric movement disorder website of *Opoclonus-Myoclonus USA and International*. As co-investigator, she helps run clinical drug trials and federally-funded investigations on pediatric and adult movement disorders. She is an experienced clinician, author of research publications, guest lecturer at national conferences, and co-founded the National Pediatric Myoclonus Center.

Goals

Our goals are to provide comprehensive, state-of-the-art diagnostic testing and compassionate care, to build a registry of **myoclonic** disorders of various etiologies to support meaningful research studies, to design and promote clinical and applied basic research in pediatric **myoclonus**, to provide patient and physician education through the use of newsletters and pamphlets, and to encourage the organization of family support groups. No other center is dedicated to the study of pediatric **myoclonus**.

Types of Disorders:

We evaluate all **myoclonic** disorders. We specialize in non-epileptic forms of **myoclonus**, not **myoclonic** epilepsy. We do treat patients with progressive **myoclonus** epilepsy, since they have both **myoclonus** and epilepsy. Because **myoclonus** has so many possible causes and affects children of any age, race, or ethnic background, we see a diverse patient population.

A Co valuation

To accomplish our goals, we have assembled experts in dozens of disciplines. Some do electrical brain wave studies (EEG and EP), sleep studies (**polysomnogram**), **neuropsychological** testing (IQ and other tests of mental function), blood tests for rare metabolic disorders and molecular genetic studies, eye examinations (**neuro-ophthalmology**), analysis of the chemicals and cells in spinal fluid (**neurochemistry** and **neuroimmunology**), measurement of movement (videotaping), determination of the source of **myoclonus** (back-averaging), studies of brain structure (Mill or CT scan), and advanced studies of brain function (PET or SPECT scan).

Insurance companies usually cover the cost of our diagnostic evaluation, and can be contacted in advance for questions.

Sometimes we can arrange a short stay for out-of-state families in our local Ronald McDonald House.

Patients from out-of-state may take advantage of "Angel" flights provided by American Airlines. Pilots donate their time to provide this service.

Treatment

After **you** leave the clinic, all of the test results will be collected. These results will help your doctor determine the best treatment for your child. If you qualify for a clinical drug trial, the medication, which is taken by mouth, will be given to you together with instructions. If you live out-of-town, these materials will be mailed. We will also make arrangements for return visits to us or with your collaborating local physician.

The therapy of **myoclonus** is as varied as the causes. We try to reverse the underlying brain disorder. If that is not possible, we provide symptomatic treatment. Some reversible causes include infections, immunologic abnormalities, **vasculitis**, and certain toxic or metabolic disorders.

We draw upon medications, such as new **anti-convulsants** and **antidyskinetic** drugs, **botulinum** toxin injections, immunological therapies, such as **IVIg**, **immunosuppressives**, **plasmapheresis**, and new anti-lymphocyte therapies.

Some patients benefit from speech therapy, physical therapy, counseling, consultation with a dietitian, or dietary supplements.

Finding Solutions through

A modern and active research program in human **myoclonic** disorders is necessary to improve treatment and find eventual cures. Your participation acknowledges your support for our research program and the commitment you share with us of finding better solutions to this difficult problem.

Pa Materials

Brochures

- The National Pediatric **Myoclonus** Center
- Movement Disorders
- **Myoclonus**
- The Treatment of **Myoclonus**
- **Opsoclonus-myoclonus** Syndrome
- Progressive **Myoclonus** Epilepsy

Single copies are free

Reprints

Our center has published many authoritative medical publications on **myoclonus**. We can provide a list of publications, which are available at medical libraries. We also provide pertinent reprints.

Newsletter

We publish two **myoclonus** newsletters to communicate new developments about **myoclonus**. The newsletters discuss common problems and solutions of interest to patients with **myoclonus**.

Information Sheets

Our center offers fact sheets on topics such as drugs to avoid because they worsen **myoclonus**, recommendations regarding immunizations, and profiles on treatment options.

Videotape Session

To help educate families and health care professionals about **myoclonus**, we show videotapes to new patients and their families during your stay. The tapes provide an overview of **myoclonus** or address a specific **myoclonic** disorder.

Consultation Network

We also started a video consultation network for the purpose of screening videotapes of potential study subjects referred by pediatricians, neurologists, nurses, or self-referred.

Support Groups

Center participants find out about support group activities. People share their feelings about coping with **myoclonus** and discuss ways to communicate with friends, families, schools, coworkers, and employers about the needs of patients with **myoclonus**.

Public Aware

Our National Pediatric **Myoclonus** Center is listed with the National Organization for Rare Disorders (NORD), the American Academy of Neurology (AAN), and the National Disease Research Interchange (NDRI). Through mailings of the Epilepsy Foundation of America (EFA), the Child Neurology Society (CNS), and journal publications and lectures, we continue to promote public awareness. For an article on **opsoclonus-myoclonus**, see "Friendly Fire" in *Discover* magazine, April 2000.



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