

Update

SPRING 2009

In This Issue:

- Euro-Peds Reunion
- Photo Album p. 3-4
- Therapy Dog Volunteers p. 2
- Words of Thanks p. 4
- "Parent-to-Parent" p. 5
- Resource Guide
for Parents p. 2
- Euro-Peds' New
Facebook Page p. 5
- 2009 Events Calendar
..... page 6

Message from the Director

As many of you are aware by now, "NOMC Euro-Peds" is now "Euro-Peds National Center for Intensive Pediatric Physical Therapy," and on November 7, 2008 we became part of the new Doctors' Hospital of Michigan. Despite the change in owners, the Euro-Peds clinic still exists in the same physical location as it has since 1999, and rest assured that we continue to provide intensive pediatric physical therapy with the same team of exceptional and specialized PTs, PTAs and Aides (with a couple of new faces!). We also accept most of the same insurances from around the country as well as Children's Special Health Care Services in Michigan.



tions for your child's therapy through The North Oakland Foundation (www.northoaklandfoundation.org, an independent 501c3 non-profit organization), you can feel secure in knowing that they will continue to maintain named accounts for patients who receive donations for therapy at Euro-Peds.

Our Euro-Peds families and referring physicians have certainly been patient supporters during this transition and I want to thank you for your faith and trust along the way. If you still have questions about the transition, please feel free to call or email me at (248) 857-6776 or mhaney@dhofm.com. Until then, I look forward to seeing you soon!

Sincerely,

Michelle S. Haney, PT, MSPT

Michelle Saunders Haney, PT, MSPT, Director

For those of you who have received dona-

Euro-Peds CP Conference at World Congress Expo

As part of our commitment to providing research and education to our families, Euro-Peds partnered with the organizers of World Congress & Expo on Disabilities to bring together seven experts in various topics surrounding pediatric cerebral palsy. We want to thank the following experts for educating the parents and professionals at WCD and for being part of the Euro-Peds CP Conference:

Dr. Dennis Steindler, Executive Director of the McKnight Brain Institute at the University of Florida, was gracious as a lunchtime keynote speaker on stem cell therapy.

Dr. David Yngve, Professor of Orthopedic Surgery & Rehabilitation at the University of Texas



Carol Huegel, PT, presents on Hippotherapy at the Euro-Peds CP Conference, part of the World Congress & Expo on Disabilities Educational conference in Jacksonville, FL in November 2008.

Medical Branch in Galveston, educated on the "PERCS (SPML)" spasticity management procedure as an alternative to invasive tendon lengthening surgeries;

Dr. Leonard Elbaum presented his PT program for teens with spastic CP; **Bruce Harter** eloquently challenged individuals to go beyond their



461 West Huron, Suite 406
Pontiac, MI 48341-1651
Toll free 888.875.6662
Fax: 248.857.7102
Email: europeds@dhofm.com
www.europeds.org

Therapy Dogs & Their Human Volunteers

Euro-Peds currently has two therapy dogs, **Kobe** and **Dutchess**, who visit weekly by way of their very committed human volunteers, **Mary Crocker** and **Ross Turner**.

You'll often find seven-year-old Kobe, a red-headed Golden Retriever rescue-dog, sweet-talking a child into holding his leash for a therapeutic walk down the hallway or being brushed by a child during warm-up activities. When not working, Kobe is often greeting guests at Mary's business, Nutech Graphics in Pontiac, Michigan, or hanging out with his 3 canine siblings (who envy

Kobe's therapy-dog road trips, as Mary explained). Kobe is certified by Therapy Dogs International (TDI, Inc).

Eight-year-old Dutchess, who also was rescued from a shelter, was trained by Doctor P.A.W.S. Pet Assisted Therapy after Ross

Ross Turner with his therapy dog Dutchess.



recognized her gentle demeanor. Ross is a teacher by day and a volunteer at Doctors' Hospital & Euro-Peds by afternoons. He is also facilitating the start-up of a Dr. P.A.W.S. Pet-Assisted Therapy training program at Doctors' Hospital of Michigan, slated to start in April of '09.

Both volunteers are very considerate of children and their parents who are not accustomed to dogs, so make sure you let your therapist know if your child doesn't prefer Kobe's or Dutchess's help.

Thank you, Mary and Kobe, and Ross and Dutchess!



Mary Crocker and Kobe with Josh at Euro-Peds

Special Needs Resource Guide

Here are some resources that parents tell us are useful, so we thought we would pass them along to you:

AblePlayers Club, www.ableplay.org, toys and play products for special needs children includes reviews and ratings for choosing appropriate toys. (recommended by Danielle Budreau, Ohio, mom to Mason)

The Humanitarian Foundation of the Grottoes of North American, www.hfgrotto.org, a Masonic organization that sponsors dental care for children with disabilities. The program helps cover the costs of dental treatment, including hospital and anesthesia costs when needed for children with CP, Muscular Dystrophy, Organ Transplant recipients, Down Syndrome, and children with significant cognitive limitations (recommended by Dawn Frasa, Michigan, mom to Darren).

Children's Neurobiological Solutions Foundation, www.cns-foundation.org, provides research

funding and information for brain repair via stem cell therapy.

Luke Billings Foundation, <http://lukebillingsfoundation.org>, a donor advised fund under the Columbus Foundation, offers financial help to Central Ohio children with CP, so they can receive ongoing and necessary therapy at established programs such as Euro-Peds (recommended by Ohio parents Lynne Fogel, Patty Lyons, Jill McQuaid, and Joanna Williams)

U.S. Department of Health and Human Services, www.hhs.gov/od/physicalfitness.html, an online mentoring program for children with disabilities called, "I can do it, you can do it!" (recommended by Barb Johnson, PT).

If you have a useful website or resource that you would like us to share with other parents in an upcoming Euro-Peds newsletter, please call: Anne Mancour, Communications Coordinator, Euro-Peds, (248) 857-6979, or email: amancour@dhofm.com

You may also post your links, books, or articles on the Euro-Peds Parents Group on Yahoo!, or on the new Euro-Peds Facebook page!

Parent to Parent *Getting Help for Children with Rare Genetic Disorder*

By Dr. Katheryn Elibri Frame, mom to Euro-Peds Patient, Kiera (born Nov. 2005)

Kiera, my first child, was born perfect head to toe! Life was going along beautifully for the first 8 weeks, and then one day, out of nowhere, she had a seizure. Our life-her life-as we knew it was about to be changed forever. Doctors and specialists could not explain the seizures that escalated to as many as six per day, and for a long time, medication had no affect.

After almost three exhausting and frustrating years of endless medication trials, blood tests, EEGs, 6 MRIs, 1 PET scan, multiple hospital admissions, a biopsy and a spinal tap, we finally had an answer: **A mutation in the cdk15 gene on the X chromosome.** Kiera's neurologist explained that it was considered a rare variation of Rett Syndrome. While I had heard of Rett Syndrome, I had not heard of CDKL5. Since Kiera's diagnosis last fall, we have learned much about this rare disorder.

CDKL5 is a rare neurological disorder characterized by early onset, medically refractory seizures, and developmental delay (only one



child has so far been identified that never had a seizure). There is a broad constellation of symptoms, and **patients may have been given the diagnosis of Infantile spasms, West syndrome, Lennox-Gastaut, Atypical Rett Syndrome, Early-onset intractable epilepsy, or even autism.** CDKL5 affects mostly girls, but there are several males known with this disorder. According to the official website on the mutation (www.cdk15.com), at least 10% - 20% of individuals with a clinical diagnosis of Autism/ASD are expected to have an identifiable genetic cause. As awareness of CDKL5 disorders spreads, more children are being tested for CDKL5.

Since learning of Kiera's diagnosis, I have joined a Yahoo support group [<http://health.groups.yahoo.com/group/CDLK5>, or email cdk15@yahoo.com to sign up] with other parents from around the world who have children affected by a CDKL5 disorder. This support group has been an amazing place for me to talk with other parents about how it has affected our lives. We share common stories and many small wonders, and cherish the accomplishments of each other's child. Together, we are in the process of forming a **not-for-profit international foundation** to begin raising public awareness, fund research and help other families that have been similarly affected.

If you think your child could have a CDKL5 gene mutation, please ask your neurologist, geneticist or pediatrician to send off a blood sample to be tested. There are several labs in the USA that test for the mutation, including Baylor and the University of Chicago. It takes about 4 to 6 weeks to get the results. In the meantime, please visit www.cdk15.com for more information.

facebook

Good news! Euro-Peds is now on **facebook!**

There are two groups - one is a group page: **Euro-Peds Parents Support Network and Other Awesome Advocates**; and the other is a Cause page - **Euro-Peds National Center for Pediatric PT**. Both have discussion boards though the Cause page is more involved - including photos, video, and a link to donate to The North Oakland Foundation. Once you're in the group, you can invite other parents and friends. This is a great way to network with other parents and share helpful information with one another!

We invite you to join! Here's how:

If you want to join the group and you already have a facebook profile: go to www.facebook.com, log in, search for **Euro-Peds**. Click on the group/cause and join it. In the event that an invite is required for you to join our cause page, please email Anne Mancour at amancour@dhofm.com to request an invite.

If you want to join the group and you are not on facebook: you need to create a **facebook** profile. Go to www.facebook.com and register. It's free! You do not have to post a picture of yourself, share your real name online or fill out any profile details if you don't want to. Just create a log in and password so you can get in to the site, then follow the instructions above.

World Congress Expo cont'd

CP diagnosis to live their lives fully;

Carol Huegel, PT, Hippotherapy Clinical Specialist, educated about the benefits and history of hippotherapy as a complementary therapy for children with disabilities;

Sylvia James-Miller, advocate and mother of disabled children, gave a heartfelt personal account of living with chronic grief appropriately entitled "A Dream Re-Born!;"

Dr. Keith Williams, Director of the Feeding Program for children with neuromuscular disorders at the Penn State Hershey Medical Center, provided an account of his successful intensive feeding program that he pioneered

Michelle Haney, Director of Euro-Peds, presented on Intensive Pediatric PT for treating children with neuromuscular disorders

Thank you again for your time and expertise.

View Dr. Steindler's stem cell therapy presentation on WCD's website:

<http://www.tvworldwide.com/events/wcd/081121/>

2009 Calendar of Events

April 17-19

Metro New York Abilities Expo & Conference, New Jersey Convention Center, Edison, NJ

Presentations: (refer to www.abilitiesexpo.com)

*Friday, 4/17 10:30am-12pm, "Intensive Physical Therapy: An Emerging Therapy in the Treatment of Children with Neuromuscular Disorders." (Professional Development)
Sunday, 4/19 10:30am-12pm, "Never Underestimate a Child: Using Intensive PT to Teach New Skills (General Conference)

May 29-31

S. California Abilities Expo & Conference, Anaheim Convention Center, Anaheim, California

Presentations: (refer to www.abilitiesexpo.com)

*Friday 5/29 (time TBD); Sunday, 5/31 (time TBD)

June 5-7

Family Café 11th Annual Conference

Presentations: (refer to www.familycafe.net) Day/Time TBD

June 25-27

**Chicago Abilities Expo & Conference
Schaumburg Convention Center, Schaumburg, IL**

Presentations: (refer to www.abilitiesexpo.com) Day/Time TBD

October

EURO-PEDS REUNION

Oakland Yard Athletic Dome, Waterford, MI
Day/Time TBD

November 5-7

**Atlanta Abilities Expo & Conference
Cobb Galleria Conference Center, Atlanta, GA**

Presentations: (refer to www.abilitiesexpo.com)
Day/Time TBD

November

Michigan POHI/SXI Conference

Day/Time TBD

* Presentations that qualify for CEU's for professionals.