

THE MAYO FAMILY PEDIATRIC PAIN Rehabilitation Center (PPRC) at the Waltham campus of Children's Hospital Boston opened in June 2008 as the most comprehensive, stand-alone program of its kind in the United States, committed to serving the needs of children, ages 7 to 18, with chronic musculoskeletal and neuropathic pain. Complex regional pain

eight hours per day, five days per week, typically for periods of up to or longer than three weeks, for intensive physical, occupational, and psychological therapies. These services are offered in both individual and group settings and are combined with family therapy and parent training. This intensive rehabilitative approach is particularly appropriate for

successfully learned to self-manage their chronic pain, replacing their experiences of disability with a sense of wellness and physical strength. No children have left the program using assistive devices, such as wheelchairs, crutches, braces, or splints, although many of them came to the program using these devices. For all of these children, returning to school full-

## Hope for Children with CRPS: The Mayo Family Pediatric Pain Rehabilitation Center (PPRC)

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syndrome (CRPS) is one of the most common diagnoses given to children presenting with this kind of pain,<sup>1</sup> and the primary focus of the center is to treat children with this specific syndrome. The PPRC's multidisciplinary approach to the treatment of CRPS integrates physical, occupational, and cognitive behavioral therapies with medical services from physicians who specialize in pediatric rheumatology, anesthesiology, and neurology. In 2,500 square feet of space, staff have use of two biobehavioral therapy rooms, two private physical therapy rooms, a physician consult room, a functional training area/gym, and a therapeutic pool with a shower and changing area.

The PPRC was specifically designed using a multidisciplinary,<sup>2</sup> partial-hospital treatment model that is customized to meet the individual needs of each child and his or her family. Children attend

the subgroup of children with CRPS who have failed to achieve pain relief or functional improvements after extensive standard outpatient treatments. Notably, children must have failed to regain use of their affected extremity(s) through traditional outpatient rehabilitation services. Many of the children who have enrolled in the program have undergone largely unsuccessful, intensive, and often invasive and costly treatments that have greatly impacted their lives, and the lives of their families, such as lengthy inpatient hospitalizations, repeated sympathetic nerve blocks and epidural catheter infusions, ketamine-induced coma, and implantation of a spinal cord stimulator.

As the PPRC approaches its one-year anniversary, the Center has become a nationally-recognized program for rehabilitation services for children with chronic CRPS. To date, more than 52 children and their families have suc-

cessfully learned to self-manage their chronic pain, replacing their experiences of disability with a sense of wellness and physical strength. No children have left the program using assistive devices, such as wheelchairs, crutches, braces, or splints, although many of them came to the program using these devices. For all of these children, returning to school full-

time, beginning to play sports, do crafts or other activities again, and socializing with peers were explicit treatment goals. All PPRC graduates have made significant progress in their ability to reintegrate into their community environment and regain their lives prior to CRPS. Specific focus during treatment is directed at helping these children gain strength and confidence in important activities of daily living, including self care, walking (with and without backpacks); writing and typing; regaining the physical strength and endurance necessary to fully engage in sports and leisure activities; and strategies for re-establishing important relationships with their family and friends. All children leave the program with individually-tailored plans for returning to school successfully, and home exercise programs for maintaining their gains in physical strength. The program's psychologists also provided specific recommendations

for accommodations for those children who needed them in order to return to school successfully. As one mother explained, “Since completing the program, she is able to participate fully in all sports and activities that she enjoys. She is a living example of how this program can help others to fulfill their dreams.” According to another parent whose 12-year-old son suffered from debilitating CRPS, “Our son cried in agony from a disabling, roughly unexplained pain in both legs that quickly rendered him helpless and confined to a wheelchair. After two months of watching our child require assistance with even mundane daily self-help skills, he was diagnosed with CRPS and entered the PPRC. The PPRC’s staff assured us that he would soon be walking again. By day three of the program, he walked out the door unassisted. By day five, he was back on his Ripstick, a two-wheeled skateboard. By the time he left the PPRC, he was running a 100-foot sprint in less than nine seconds, a feat he couldn’t do even before he had CRPS.”

In addition, the PPRC conducts scientific research on the mechanisms underlying CRPS, including an active collaboration with an international pain research group that conducts functional magnetic resonance imaging (fMRI) of the brain in an effort to understand relationships between brain structure and function in children who experience chronic pain.<sup>3</sup> To date, more than 10 children enrolled in the program have received magnetic resonance images of their brain, both when they entered and when they left the PPRC. We hope that this “before and after” imaging will add to our understanding of why some children develop CRPS as a consequence of suffering injury, and the extent to which these same children can successfully rehabilitate themselves in a multidisciplinary rehabilitation program.

Additionally, the PPRC’s therapists, physicians, and nurses actively engage in clinical research to evaluate the many therapeutic factors resulting from the ongoing physical, occupational, and

psychological factors that may be related to pain, such as depression and anxiety.

We sincerely thank the Mayo family for their generous support without which the



*Team PPRC at the Achilles Walk for Hope & Possibility on June 28.*

psychological therapies, which may affect children’s clinical outcomes or program success. Assessments designed to quantify changes in physical ability, medical, or psychological functioning are administered routinely at intake, discharge, and follow-up evaluation periods of one and four months. Examples of these assessments include the Bruininks-Oseretsky Test of Motor Proficiency, Second Edition,<sup>4</sup> the Lower and Upper Extremity Function Scales,<sup>5-6</sup> and the Canadian Occupational Performance Measure<sup>7-8</sup> in physical and occupational therapy. The Functional Disability Index (FDI),<sup>9</sup> the Children’s Depression Inventory (CDI),<sup>10</sup> and the Multidimensional Anxiety Scale for Children (MASC),<sup>11</sup> are used to assess

PPRC would not have become a reality. With their continued support, we look forward to both expanding clinically, and through continued research, improving upon our understanding of this syndrome and our ability to help children with CRPS. We are able to move forward with innovative clinical and research programs that are designed explicitly to offer the best multidisciplinary treatments for CRPS to children and their families affected by a diagnosis of CRPS.

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important to Andrea. She wanted to go to school since she was 5 years old.

There were many nights I slept in the dorm room with her because she was in so much pain and didn't want to be alone. But she was so determined. She never gave up."

Both awards will be given in January 2010. Award applications have been slowly trickling into the organization, but both Leslie and Gus hope that with greater awareness, more people with CRPS can benefit from the funds. "The more people that know about Fighting "4" Us, the more that we can help them," declares Gus.

It's easy to see where Andrea got her dedication and persistence, although her parents would say otherwise. "People have said to me 'you've done everything for Andrea and helped her get through.' I've always said that Andrea got us through. It was her determination. There were times when her CRPS was so bad and she wanted to give up and she could barely stand it. But her overall attitude and her overall behavior was to just keep on fighting," explains Leslie.

Just as Gus and Leslie are raising interest in Fighting "4" Us, their daughter was also intent on rallying others to the cause and increasing the membership as she notes in the organization's mission, "Now the one thing missing from this organization is you. You are the reason we began this organization, and you are the reason why we will keep it going...I truly believe this dream will come true, and with your help it will, and we will beat this disease known as RSD." Powerful words and extraordinary vision from a leader gone too soon.

*Further information and applications for both awards can be found on the website, [www.fighting4us.com](http://www.fighting4us.com); the submission deadline is December 1, 2009. ■*

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