

educational opportunity, you will meet many other people who understand your experience in a way that no one else does. People who meet at our symposia have developed lifelong friendships. If you have been to our symposia in the past, then you understand why you need to try to make it back.

Please check the main page of The Transverse Myelitis Association web site, as we will post updated information as it becomes available. We are looking forward to seeing you in Dallas this fall!



Dare to Get Out of the Chair!

Cody Unser invites you to participate in a ***Discover Scuba Event*** for "Symposium Participants" on ***Friday Evening, September 24, 2010, at the Westin Galleria.***

Enroll today! Space is limited and only offered to participants of the 2010 Rare Neuroimmunologic Symposium hosted by the University of Texas Southwestern.

Don't miss your chance to try Adaptive Scuba with Cody's Dive Team,

Operation Deep Down, who have trained students from Riley Children's Hospital, VA Hospitals, Paralyzed Veterans of America, NM Association of Blind Students, and many more! Now it's your turn to join this elite group of Adaptive Scuba Divers and Cody is thrilled.

Students will ***Discover Scuba in a team of two***...so you can try scuba with a "dive buddy" who can be a family member, friend, caregiver, or you can choose to dive with one of our many volunteers!

Who: Registrants of the 2010 Rare Neuroimmunologic Symposium

What: Discover Scuba Event – Adaptive Scuba for the Disabled

When: Friday Evening, September 24, 2010

Where: The Westin Galleria Pool

How: Enroll today at www.codysfirststep.org

Click "Contact" on the left menu bar and fill out the form. Ensure your message says... "I am enrolling in Discover Scuba Event at the 2010 Rare Neuroimmunologic Symposium."

Those of you who choose the dry-side of our event are welcome to watch and see how Adaptive Scuba changes lives one dive at a time!

Sponsored by The Cody Unser First Step Foundation

Experimental Surgery Performed to Repair Nerve Function of 6 Year Old with TM

Daniel Becker, M.D.¹, Allan J. Belzberg, M.D.² and Sandy Siegel

¹The International Center for Spinal Cord Injury, Kennedy Krieger Institute and the Transverse Myelitis Center, Department of Neurology, ²Department of Neurosurgery, Johns Hopkins University School of Medicine.

This story was first reported by the ABC News Medical Unit (Courtney Hutchison) on Monday, March 29, 2010; "Experimental Procedure 'Rewires' 6-Year-Old's Nervous System: Surgery May Restore Movement to Child's Paralyzed Arm."

A six-year old with transverse myelitis from Pennsylvania underwent an experimental surgical procedure to rewire the nerves in his right arm. The boy had strep throat in September 2009 which was subsequently followed by an inflammatory attack in his spinal cord. During the attack, he lost function in both arms; his left leg and he lost the ability to breathe on his own. He received a transverse myelitis diagnosis.

Over the next six months, he regained function in his neck, his left side and he regained some use of his right hand. His right arm, however, was not regaining function. In transverse myelitis, about a third of patients will regain most of their neurological function, a third will have moderate disability and the remaining third will have significant permanent disability. This 6 year old boy had severe weakness on his left side, breathing difficulties and paralysis of his right arm and shoulder after six months. After six months, his chances of regaining significant right arm function in the near future were poor. After administration of acute therapies, such as intravenous steroids, IVIG or plasma exchange, the only treatment available is aggressive physical and occupational therapy (i.e., activity based restorative therapies) to try to increase the function of the remaining intact nervous system.

After 6 months, his parents, in consultation with the physicians at Johns Hopkins and the Kennedy Krieger Institute, decided to proceed with an experimental surgery. The purpose of the surgery was to allow the boy to bend his arm using a new rewired nerve which was taken from his leg. In the five hour surgery which took place in March 2010, nerve tissue was taken from his leg and was used as a graft to reroute a nerve in his shoulder to control his right arm. This was only the third time that a nerve transfer operation has been used to treat a patient with TM; the previous two cases also having been performed at Johns Hopkins. The surgeon was Dr. Allan Belzberg, Associate Professor of Neurosurgery, Johns Hopkins University School of Medicine. The surgery went very well, but it is too early to tell if the goal has been achieved. It will take months for the boy to recover.

The idea for this procedure came about two years ago at Kennedy Krieger Institute and Johns Hopkins Hospital. A TM neurologist was sitting at lunch discussing a challenging case. The neurosurgeon at the table suggested the child be treated like traumatic injured children he sees. The chance lunch encounter lead to the novel approach to TM. The concept consists of using a nerve that is healthy and working under voluntary control and reroute it into muscles that have lost their voluntary motor control because of injury. A large number of children with transverse myelitis are cared for at the International Center for Spinal Cord Injury, Kennedy Krieger Institute (KKI) through its association with the TM Center at Johns Hopkins. Dr. Becker serves as both the Director of the Pediatric Spinal Cord Injury Unit at KKI and as a physician at the TM Center at Johns Hopkins Hospital.

Over the past few years, we have encountered a number of children who suffered from idiopathic TM who presented with arm and leg weakness. These children then recovered almost completely normal function with the exception of one arm, or in one particular case, one leg. The arm that did not regain function remained extremely weak proximally while recovering hand function. While it was great for these children to have recovered so much function overall, they were left with one basically nonfunctional extremity;

and which caused them a great deal of difficulty in their day to day lives.

At KKI, we have the tremendous benefit of working with the Brachial Plexus Clinic. This clinic is comprised of a neurosurgeon, Dr. Belzberg, an orthopedic surgeon, a plastic surgeon, and several other rehabilitation experts. Traditionally, the clinic has provided care to children with brachial plexus injuries that are usually caused by birth trauma or other traumatic injuries, such as car accidents or falls. The brachial plexus is a network of nerves that conducts signals from the spine to the shoulder, arm, and hand. Brachial plexus injuries are caused by damage to those nerves.

The nerve graft should allow the boy to bend his arm when his brain sends the message to 'shrug my shoulder.' His arm will not return to totally normal function but he should be able to bend his arm. His movements should improve and become more natural in time with practice; he will have to relearn to use his arm. He may lose some strength in his right shoulder where nerves were rerouted and he may have a numb patch on his left foot where sensory nerve fibers were taken from his left leg for the graft. The surgical procedure did have risks. It was technically a very challenging operation. There are unique differences between people's nervous systems and there is a risk of damage to nerves that are functioning properly or the blood vessels that are connected to those nerves and are vital to their survival.

It will take a very long time for the nerves to regenerate. Nerve growth takes place at about one inch per month, so it will be about six to eight months before we begin to observe any changes. We will also use very aggressive physical and occupational therapy to strengthen his arm and help with coordination. It helps a lot that the boy is so young. The nervous system is very plastic; it learns quickly. The younger a person is, the easier the learning will be. We will have to train a muscle that functioned in one way (in a leg) to now function in another (his arm).

We do not know yet how successful this overall approach will be. There is also a very significant question about the perfect timing for scheduling a surgery of this type. On the one hand, we want to give the patient sufficient time to see what the natural/spontaneous recovery will be. On the other hand, the surgeons prefer to do nerve transplants earlier on because they feel that they will be more successful. If a long time has passed by since the injury, other surgical approaches remain viable options, such as transferring muscles and tendons rather than nerves.

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