

SCINews

A publication by the Spinal Cord Injury Program at Mary Free Bed Rehabilitation Hospital.

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Mary Free Bed First in Midwest to Offer Biofeedback for Neuromuscular Re-Education

We are proud to announce the opening of our Biofeedback Laboratory for Neuromuscular Re-education. Mary Free Bed is the only facility in the Midwest – and one of just seven in the nation – to offer the therapy, which is designed for patients with non-degenerative, non-progressive neurological disabilities.

Mary Free Bed's new laboratory was created in conjunction with Bernard Brucker, PhD, ABPP, from the University of Miami School of Medicine. Dr. Brucker pioneered the procedure for biofeedback neuromuscular rehabilitation in 1969. Known as the "Brucker Method," the procedure is based on operant conditioning and is designed to teach individuals to use motor cells in the brain, brain stem and spinal cord more efficiently.

The laboratory is led by biofeedback therapists Brittany Moore, MA, OTR, and Megan Potter, DPT, both of whom trained for four months under Dr. Brucker in Miami.

"The Biofeedback Laboratory is an exciting addition to the scope of services we offer at Mary Free Bed," says John Butzer, MD. "It offers new hope and freedom to people with certain disabilities. The possibilities are exciting, and our hope is to positively impact the lives of many."

How It Works

The biofeedback program shows the most promise for patients with neurological disabilities caused by spinal cord injury, brain injury, stroke, cerebral palsy, spina bifida, Guillain-Barré syndrome, encephalitis, myelitis, polio/post-polio and Bell's palsy.

"The most remarkable part about neuromuscular rehabilitation is that it is not a time-sensitive therapy – there is no window of opportunity that can be missed," says therapist Megan Potter. "Actually, for spinal cord patients, a longer period of time between the injury and the use of biofeedback may be beneficial. Biofeedback offers hope to patients who may have stopped seeking alternative solutions or who may feel it's too late to attempt rehabilitation."

The process of neuromuscular feedback begins with an evaluation that enables therapists to develop a personalized plan of care. The plan is carried out using a special Electromyography (EMG) Biofeedback System that helps identify voluntary muscle control. Through visual and auditory feedback, patients learn how to reproduce, maintain, and control EMG responses to maximize muscle function.

"Ultimately, we help the brain reconnect with parts of the body it is not communicating with," says therapist Brittany Moore. "The feedback, combined with behavioral conditioning techniques, helps patients to re-educate their muscles."

To Learn More

The Biofeedback Laboratory for Neuromuscular Re-education is the latest example of Mary Free Bed's commitment to offering patients hope and freedom by offering cutting edge treatment. The lab is located at 350 Lafayette SE in Mary Free Bed's Outpatient Therapy Center. To learn more about the service, which is available only through a physician prescription, please call 616.242.0392 or 800.528.8989.

Ask the Doctor

By Sam Ho, MD

Spinal Cord Injury Program, Medical Director



"One of my spinal cord injury patients recently asked me for information regarding the experimental surgery that Dr. Hongyun Huang is doing in Beijing, China. While doing some reading on spinal cord injury research, I came across this informative article, from The

Miami Project, which I highly recommend to my patients considering this procedure."

CLINICAL STUDIES ABROAD: WHAT CAN WE LEARN?

Recently there has been news from various countries of the effects of transplanting olfactory ensheathing cells (OECs) into people with spinal cord injury (SCI). Of note to the scientific community are anecdotal reports that people who have undergone these procedures have had improvements in sensory and motor function within the first days after the procedures. While there is interest within the scientific community, these anecdotal reports are leading to more questions than scientific answers.

Several studies in animals support the idea that OEC transplants may increase function, thus leading some doctors in other countries to offer such treatments. Because these experimental surgical procedures are both invasive and permanent, many scientists feel that transplanting these cells in humans is premature. There are numerous questions about the effectiveness of the procedures and concerns about potential adverse effects. The Miami Project has been asked its opinion of these procedures. While more information is required before safety and efficacy can be ascertained, The Miami Project has taken the position that there may be an opportunity to advance scientific knowledge from these clinical experiences if more comprehensive information can be obtained. The following explains this position in relation to one of these experimental procedures.

Experimental Transplant

One experimental transplant that has gained the attention of people with SCI, the media, and scientists is that of Dr. Hongyun Huang in Beijing, China. In February 2004, representatives from The Miami Project had attended the Clinical Trials Workshop sponsored by the International Campaign for Cures of spinal cord Paralysis (ICCP) where Dr. Huang was among several

clinicians who presented their experiences with experimental treatments in humans with SCI. Following this meeting, The Miami Project decided to initiate open communication with Dr. Huang to more completely understand his transplant procedure using olfactory bulb-derived fetal cells as a means to promote recovery of function following SCI. Miami Project scientists and other researchers have been experimenting with OECs as a potential cell therapy in experimental models of SCI, however, limited data were available concerning the clinical use of these cells.

A first step in this information-gathering effort was to invite Dr. Huang to The Miami Project to present a lecture summarizing his clinical experiences. Dr. Huang presented a lecture, entitled *Transplantation of Olfactory Ensheathing Glia in Patients with Spinal Cord Injury*, where scientists and clinicians had the opportunity to listen to his presentation and ask specific questions regarding procedures and outcome measures. Although this presentation provided new information including the suggestion that some patients experience functional benefit, many important scientific questions were left unanswered and led to various concerns. One concern was the lack of appropriate outcome measures that would adequately assess any long-term benefits. Another was the lack of follow-up information that would help determine the incidence of adverse effects of the procedure.

Direct Observations

Large numbers of individuals have undergone these procedures in Beijing. In an effort to obtain better scientific data, The Miami Project faculty decided it would be important to obtain first-hand information concerning the procedures and the clinical effects. To this end, two scientists/clinicians within The Miami Project traveled to Beijing and, over a ten-day period, had the opportunity to observe twelve patients, evaluating six of them for neurological function before and after surgery. It is important to note that several patients demonstrated a modest degree of improvement in motor and sensory function. Interestingly, this improvement in neurological status occurred immediately after the surgical procedure. In addition to these positive findings, some adverse effects were also observed. For example, wound breakdowns were noted in two patients, one of whom had a reduction in leg function after surgery. Meningitis occurred in another, however, the Chinese doctors did not record these complications in the patient's medical records.

The Miami Project's representatives had the opportunity to observe what they describe as a relatively simple surgical procedure of cell injections into the spinal cord of four different patients. While they did have the opportunity to witness the surgical procedures and

examine some patients, they were not permitted access to the laboratory where the cells for transplantation were prepared. Therefore, little information is currently available concerning the cellular content of these human fetal olfactory bulb cultures. One cell preparation, however, that was not transplanted into a patient was provided to The Miami Project for analysis. This analysis has been initiated and is ongoing. At this time, apart from descriptions from Dr. Huang, researchers can only guess at the important aspects of the preparation such as: What method of cell processing was used? Does the transplant tissue actually contain OECs? In what stage of development are the cells?

Unanswered Questions

Even after having the opportunity to directly observe patients and the procedure, there are still many important questions that need to be answered that are critical for scientific understanding. A major limitation of Dr. Huang's work is the lack of long-term assessment of neurological function. It appears that patients who undergo the surgery do not have a set schedule to return for follow-up assessments. Apparently, the only data collected is obtained immediately following the surgery, therefore, it is unclear if the benefits experienced in the short-term are maintained over time. Without consistent follow-up data in all patients, few conclusions regarding the long-term benefits and safety of this surgical procedure can be made.

Additionally, when considering invasive surgical procedures in people with SCI, it is of utmost importance to understand the potential complications and risks of the procedure. The detection of adverse effects requires careful and consistent documentation. Presently, it does not appear that data related to adverse effects are being systematically collected and documented by the Chinese group. Therefore, if adverse effects such as neuropathic pain or tumor formation are occurring in this group of patients, these effects may not be detected and reported.

While questions remain about the benefits and potential risks of this procedure, the observation that some functional improvements occur soon after the surgery is intriguing. The reason for these early improvements is unknown. One explanation for rapid neurological improvements in some patients may be a trophic or nourishing effect. The transplanted tissue may be secreting growth factors that enhance nerve signal conduction in the synapses or along the axons. To better understand if a trophic effect is responsible for the functional improvements, researchers will need to conduct studies on the cells used for transplantation to determine if they actually release neurotrophic (nerve nourishing) factors. If this can be confirmed, it would provide a clearer rationale for their use.

What Have We Learned?

Because accurate and conclusive information concerning the surgical protocol, methods of cell processing, and the long-term safety and efficacy of this procedure is lacking, The Miami Project's faculty do not endorse this procedure and at this time would not advise individuals to undergo this surgical transplantation strategy. While some people with SCI will view current experimental procedures abroad as their only hope, by participating they may be putting themselves at risk as well as potentially disqualifying themselves from participating in future more promising and well-designed clinical trials.

Presently, Dr. Huang's work would not meet the standards for clinical trials set by the FDA or European regulatory agencies. His work should therefore be viewed as a series of clinical treatments rather than a clinical trial. This is a very important distinction since a clinical trial would allow for definitive conclusions while a treatment series cannot. To properly assess this treatment, a more rigorous clinical trial is required; one that includes specific outcome measures and comparisons to a control group. It would also include accurate documentation of whether adverse effects occur over the long-term.

While there may be disagreement among clinicians and researchers as to when and which promising pre-clinical strategies should be advanced to clinical trials, it is important to emphasize that scientists all over the world are coming together to develop valid clinical trial guidelines for treatments targeting SCI. ICCP supported and funded the international Clinical Trials Workshop on SCI in Vancouver that brought a varied team of researchers and clinicians together to discuss progress in clinical trials and the complexities involved in effective clinical trial design. A report of this meeting was peer-reviewed and published by J Steeves, J Fawcett, and M Tuszynski in 2004 (*Spinal Cord* 42: 591-597). As a result of this meeting, an international advisory panel was created to develop more detailed guidelines on how to conduct future SCI clinical trials in the most accurate and effective manner.

It is hoped that further information coming from individual clinical studies as well as continued research into this important and exciting field will stimulate well-controlled multi-center trials utilizing the appropriate safety and outcome measures. Well-designed FDA-approved clinical trials will minimize the chances of a procedure being harmful to the patient and will maximize the opportunity to document long-lasting improvements in the future. Only through a strategy such as this can evidence-based medicine be advanced, and the safest and most effective treatments be advanced to the clinic and applied.

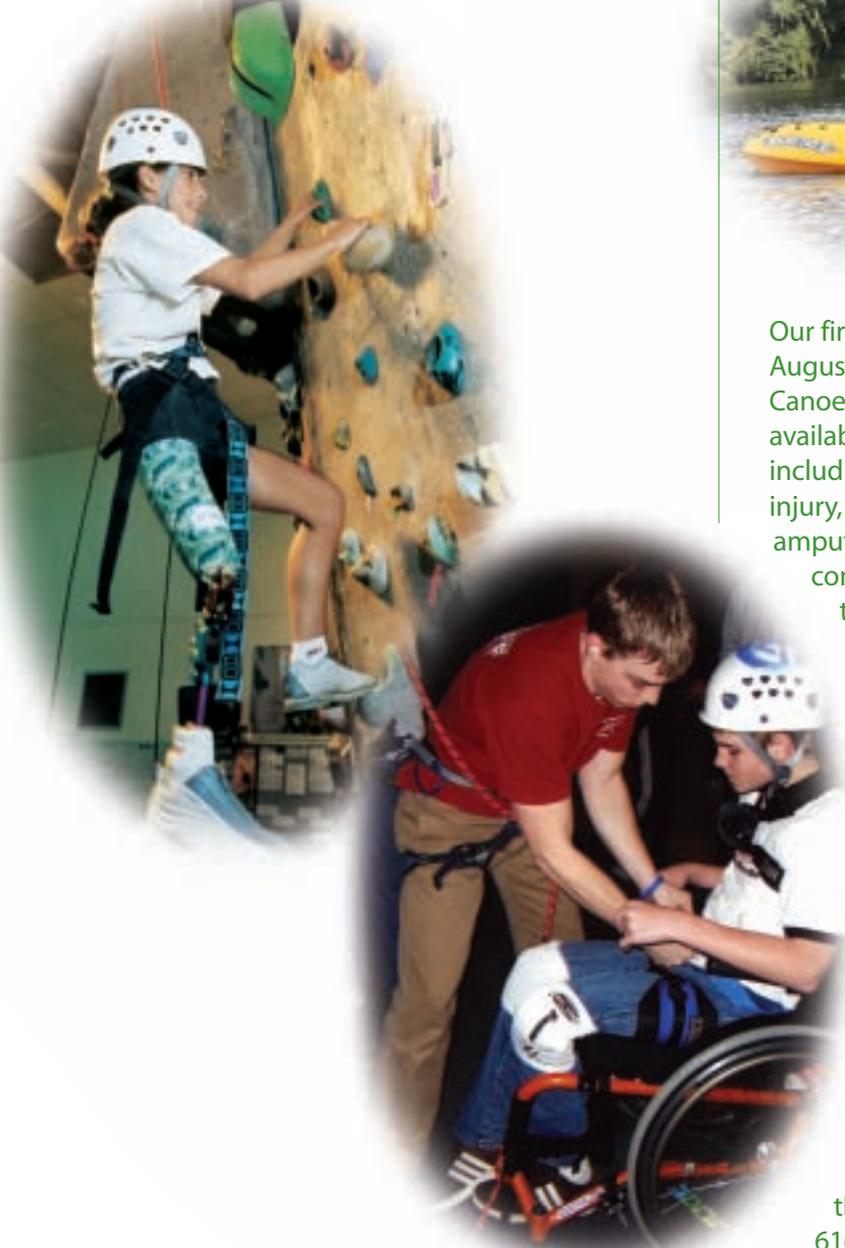
Reprinted with permission by The Miami Project to Cure Paralysis.

Event Information

Community Recreation Programs

Our community recreation program has been running full tilt! Some of the great events we've been involved with are adapted water skiing, golf, rock climbing (first annual), and kayaking and canoeing (another first!).

Our first adapted **Rock Climbing Clinic** was held on February 25, 2005 at Grand Valley State University. Rock Climbing for the disabled is a growing sport throughout the United States. Participation in this sport is particularly appealing to individuals with disabilities because it offers a physical workout, upper body strengthening and a leisure opportunity.



Our first adaptive **Canoe and Kayak Clinic** was held on August 27, 2005 at Pioneer Trails Camp in Muskegon. Canoeing and kayaking are sport activities that are available to individuals with various types of disabilities including spinal cord injury, visual impairment, brain injury, stroke, cerebral palsy and those that have had amputations. The opportunities for recreational and competitive canoeing and kayaking and recognition of these sports as serious athletic disciplines continues to expand.

Our adaptive **Water Ski Clinics** occurred on July 15 and August 1, 2005 at Little Pine Island Lake. Water skiing as a sport for the disabled is a growing athletic activity throughout the United States. Disabled skiers include those who are blind, have had amputations, stroke, brain injury or spinal cord injury. It's an exciting time as the number of recreational and competitive skiers begins to expand and recognition of the sport as a serious athletic discipline increases.

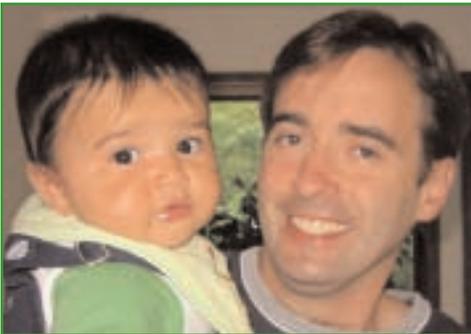
If you are interested in getting info on any of these programs for next summer, please call 616.356.1861 or visit www.maryfreebed.com.

Alumni News



Bryan Barten (1995) was back in Grand Rapids recently to compete in the wheelchair tennis tournament. He is currently ranked #7 in the world. Bryan graduated in 2002 with his Masters

in Rehabilitation Counseling. He is working at the Disability Resource Center at the University of Arizona (Disability Access Consultant). He is a member of the USA National Wheelchair Tennis Team and plays wheelchair tennis and rugby for the University of Arizona. His hobbies include traveling, snorkeling, sailing and flying gliders. He is working on getting his pilot's license. Bryan lives in Tuscon, Arizona.



Adam Grassl (2001) happily announces the birth of son Mikey (September 25, 2004). He married Patty on May 15, 2003 ("a

wonderful day!") in Texas where Patty grew up. Adam has been keeping busy with his business, Spartan Medical Supply (www.spartanmedicalsupply.com). Adam, Patty and Mikey reside in Mattawan, Michigan.

Rich Hamill (1992) reports that he is doing very well in Gilbert, Arizona ("working out hard and trying to get in the best shape I have been in, since my chair"). He is working at Scottsdale Insurance Company as a Liability Claim Representative and received the City of Scottsdale Employee with Disabilities Employee of the Year award last October. Rich is still doing motivational speaking – he closed out our SCI Symposium 2004 with his excellent presentation: "From the Eye of the Patient – Surviving to Thriving." His most recent presentation was to a group of able-bodied University of Phoenix students on "How to Take Ownership of Your Life."

Nick Long (2002) has been very busy! He continues to work in the IS department at Covenant Hospital and has started



his own medical supply and DME company, Fusion Medical (www.fusion-medical.com), with Brian Sheridan. Nick enjoys hand cycling and playing quad rugby and is on Michigan's Great Lakes Storm rugby team. Nick coordinated a quad rugby demonstration prior to the Grand Rapids premiere of the movie *Murderball* and participated in our panel discussion on rugby and adaptive sports after the movie. Nick is also very active in our peer support program.

Brian Sheridan (1994) also plays quad rugby with the Michigan team and just started a new position as the Coordinator for Clinical Research and Specialty Rehab at the Rehabilitation Institute of Michigan. Brian is working with the Proneuron ProCord study, Dr. Lima's (Portugal) OEG transplant patients, and the Center for Spinal Cord Injury Recovery. He started Fusion Medical with Nick Long and is also doing consulting through Sheridan Rehab Solutions, LLC. Brian is on the Board of Michigan Sports Unlimited (www.misportsunlimited.com).

Stay in Touch

Send your personal news and updates to:
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Please send your updates complete with your name, address, phone number and year you graduated from Mary Free Bed Rehabilitation Hospital.



Staff News

Kristen Duthler, RN, had a beautiful baby girl, Elyse, on April 25, 2005.

Mark Grab, PT Assistant, was named "Outstanding Clinical Instructor" for the 2004-05 academic year at Kellogg Community College Physical Therapist Assistant Program. Mark just celebrated his employment anniversary – 19 years with Mary Free Bed!



Jessica Hansen, RN, married Brian Sneller on August 5, 2005.



Kristy Simpson, PT, raised over \$2,200 for breast cancer research by participating in the Breast Cancer 3-Day. She partici-

pated with over 2,100 others in this 3-day, 60-mile walk on July 15, 16 and 17. This group raised over 4.3 million dollars!!! (So this is what PT's do on their free time...)



Ms. Wheelchair Michigan Competition

Jocelyn Dettloff came through Mary Free Bed eight years ago due to a T-5 complete spinal cord injury which she acquired sledding down a sand dune in Namibia, Africa. After completing all her rehab therapy, Jocelyn jumped back into life. "Believe me, laying in a hospital bed eight years ago, I never would have imagined that my life could be as "normal" as it is today," says Jocelyn. She is currently the Development Director of Disability Advocates of Kent County, plays wheelchair tennis, is a board member of the Grand Rapids Wheelchair Sports Association, and most recently was crowned Ms. Wheelchair Michigan 2005.

"The Ms. Wheelchair Michigan contest is NOT a beauty pageant," Jocelyn explains. "In fact, when I first heard about it I did not want to compete because I thought it was a beauty contest. However, I found out more about it and discovered that it is an opportunity to celebrate women who are full-time chair users, their accomplishments and living their lives with their disabilities. The contest is for women ages 21 to 60, married or single." **The Ms. Wheelchair Michigan program is recruiting contestants for the 2006 pageant which takes place in March 2006 in Southfield, Michigan.** Women from all over the state who use a wheelchair full-time are encouraged to apply. For more details visit www.mswheelchair.org. "I'd like to see this be the best year yet for the Ms. Wheelchair Michigan competition. So, ladies, sign up today!"



iBOT™ Update

Mary Free Bed Rehabilitation Hospital is thrilled to be the first evaluation and training center in Michigan for Johnson & Johnson's revolutionary INDEPENDENCE® iBOT™ Mobility System. Since

December 2004, our PT's (Charlie Hansknecht, Tim Lesch, Chris Potter and Bindu Thamman) have

done nearly 20 iBOT™ evaluations. The iBOT™ 4000, developed by J&J company Independence Technology,

is a patented gyro-balanced personal mobility system that provides new levels of freedom and accessibility for people with disabilities. It encompasses five functions not found together in any other mobility device on the market. It allows individuals to go up and down stairs, climb curbs (as high as 5"), speak with others or travel at an elevated eye-to-eye height while in a seated position, easily fit under a table or desk and travel over uneven terrain (such as sand, gravel, grass or thick carpet). It is specifically designed to allow users to be transported in a wheelchair-accessible vehicle while remaining seated in the Mobility System. The iBOT™ 4000 Mobility System is available for individuals who have mobility impairments and the use of at least one upper extremity.

Interested?

Call the Independence Technology Customer Zone toll-free at 866.813.0789 or visit www.ibtnow.com.

Candidates will be screened and then referred back to Mary Free Bed for an assessment.

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