

SCI News

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

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Pictured left to right: Sam Ho, MD, Mary Free Bed Spinal Cord Injury Program medical director with Spinal Cord Injury Symposium guest speakers, Susan Harkema, PhD, and Wise Young, MD, PhD

2008 SCI Symposium *The Road Wide Open – Rehab, Research, and Recovery*

On Friday, September 19, Mary Free Bed's Spinal Cord Injury Program presented an all-day Spinal Cord Injury Symposium. This educational event brings together top experts in the field to highlight the latest developments in spinal cord injury care. This year's symposium, held at the Crowne Plaza of Grand Rapids, attracted nearly 200 SCI survivors, family members, physicians, therapists, and other health care providers.

"We chose the title *The Road Wide Open* because it speaks to Mary Free Bed's mission of restoring hope and freedom for people with spinal cord injuries," explained Jackie Wondolowski, Spinal Cord Injury Program manager and symposium committee chairperson. "We wanted to focus on three key areas of interest – what's new in SCI rehab, what's happening

around the world with SCI research, and what's being seen with SCI recovery. We also wanted to highlight our own innovative services, especially our Intense Therapy for Motor Recovery Program, and include an SCI survivor panel discussion so that our newly-injured patients could benefit from their peers' knowledge and experiences. Additionally, our symposiums always offer those who attend opportunities to meet with vendors and learn about the latest in high-tech equipment and other resources."

It's important to the symposium committee that SCI survivors and family members are provided the opportunity to attend the conference at a reduced rate. "People with SCI and their family members and caregivers can really benefit from the information presented at our symposiums," Wondolowski said. "We want to ensure that cost isn't a barrier to attendance."

Mary Free Bed's spinal cord injury team works together to make sure that their inpatients can attend. "Our current SCI inpatients should attend the symposium, if they're medically able," remarked Sam Ho, MD, Spinal Cord Injury Program medical director. "Newly injured patients really benefit from the day because they can gain a lot of knowledge about their injuries, current treatment approaches, and SCI research. Additionally, they're able to practice skills they're working on in therapy in a community setting with team members available to help them, and they have opportunities to talk with our former patients. This kind of peer contact is really helpful because they can hear first-hand how others with similar conditions deal with their injuries."

Hope in SCI Research

Wise Young, MD, PhD, recognized as the world's top scientist and researcher in the field of spinal cord injury, opened the symposium with his compelling presentation entitled, *The Basis for Hope in SCI Research*. Dr. Young is the founding director of the W.M. Keck Center

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for Collaborative Neuroscience at Rutgers, The State University of New Jersey. As one of the world's outstanding neuroscientists, he has appeared on many nationally televised news programs and his work has been featured in numerous publications. He's also the recipient of multiple national and international awards.

To highlight the great advances in spinal cord injury care and research over the years, Dr. Young reviewed the history of spinal cord injury medicine beginning with the first documented reference to this condition in 3000 BC, when spinal cord injury was first described as a condition "not to be treated." Clearly demonstrating a passion for his field, including an extensive knowledge of prior and current research, Dr. Young emphasized the many advances that have been made over time, including developments in surgical, medical, rehabilitative, regenerative, cell transplant, and remyelination therapies.

"...fighting to change the attitude of 'nothing can be done.'"

According to Dr. Young, since 1995 (the year Christopher Reeve was injured), tremendous progress in

spinal cord injury research and rehabilitation has been made. He shared how his life's work has involved "fighting to change the attitude of 'nothing can be done.'" Dr. Young explained that due to new technology and improved vehicle safety standards, the overall incidence of spinal cord injury is down. Additionally, Dr. Young continued, "The percentage of complete spinal cord injuries has dropped from 67 percent to 37 percent due to earlier decompression [of the spinal cord post-injury] and better medical management of patients. We've seen a change in surgeries [improved techniques; better hardware]. We're not making patients immobile for so many weeks after injury; we're not putting people in bed for three months. Now, patients are sitting up the day after their injury, and are being sent from acute care to rehab in a week instead of waiting months."

As part of the team that discovered and established high-dose methylprednisolone as the first effective therapy for spinal cord injuries, a significant breakthrough and universal standard of care for early intervention with traumatic injuries, Dr. Young is a recognized expert when it comes to the history – and future – of SCI treatment. "We're not sitting still," Dr. Young reported. "Many treatments [for spinal cord injury] were discovered in the U.S. in the past 15 years."

In response to the question, "will there ever be a cure for spinal cord injury?" Dr. Young strongly emphasized the importance of the medical community getting as many clinical trials going as possible. He explained that greater numbers of clinical trials increase the likelihood for success. "Cast the dice as many times as possible. The more you toss the dice, the greater the chance you will win. If one person wins, everyone wins. But, we have to do good science and be rigorous," Dr. Young said.

Dr. Young spoke about the different types of research and medical procedures being done around the world, including his recent work with the China Spinal Cord Injury Trial Network. (Visit the Rutgers Web site listed in the *SCI Resources* section.) He noted that since 9/11, money for U.S. research has dried up. Some individuals are traveling overseas, especially to China, to undergo experimental treatment, including surgery. Dr. Young cautioned those in attendance about this growing trend of "medical tourism," or going to foreign countries to participate in non-FDA approved procedures. There is concern that this could make people ineligible for participating in U.S. government approved clinical trials.

Geoff Newmyer, a current Mary Free Bed outpatient, was injured in a hunting accident a year ago. Recently, Geoff spoke about the symposium during one of his therapy sessions. While his legs pedaled the Ergys bike by means of electrical stimulation, he said, "We just don't do trials [in the U.S.] like they do in China. It's my understanding that if you go to China or somewhere else overseas for a trial then you may not be eligible for [participating in] a trial in the United States."

Geoff Newmyer pedaling the Ergys bike.



Dr. Young also discussed spinal cord regeneration, "With complete spinal cord injury, you need regeneration. In 2005, there were over 100 therapies that focused on regeneration in animals and almost none have gone to trial for humans."

Dr. Young explained that there are three known obstacles to regeneration: the site of the injury itself and the need to make the site hospitable to axonal (nerve) growth; time, as axons grow slowly and need sustained growth for years to reconnect; and growth inhibitors. "Each of these things needs to be taken to clinical trial and tested," said Dr. Young.

As for stem cell transplants, Dr. Young remarked, "They are very controversial, even in China." He also noted that a major problem continues to be immune system rejection of the cells, and questioned whether the risk of being on life-long immunosuppressors is worth the benefits. Dr. Young currently is working on a trial that incorporates using low-dose lithium with umbilical cord blood. His goal is to have a phase III clinical trial in the U.S. in 2009 with 400 patients.

"Many therapies show promise in regenerating and remyelinating the spinal cord."

"Many therapies show promise in regenerating and remyelinating the spinal cord," said Dr. Young, at the conclusion of his presentation. "Several

therapies are ready to go to clinical trial. Combination therapies are likely to be needed. Much work needs to be done to prepare other therapies for clinical trial. Industry sponsorship of spinal cord injury clinical trials is beginning. The first successful therapy will transform the field [of spinal cord injury treatment]."

"I really liked Wise Young's philosophy and ideas on clinical trials," said Newmyer. "His eyes have seen it [research outcomes]. I would do a clinical trial if I knew it was safe. Wise Young knows his stuff. From what I learned, I think it will be a combination of things that will regenerate the spinal cord. I think the research is already out there and I'm just waiting for it to come to trial."



Evidence and Application for Activity-Based Therapy

Susan Harkema, PhD, a leading researcher in the field of neurological rehabilitation, presented *Evidence and Application for Activity-Based Therapy*. Dr. Harkema is an associate professor in the Department of

Neurological Surgery at the University of Louisville, rehabilitation research director at the Kentucky Spinal Cord Injury Research Center, and director of research at the Frazier Rehab Institute in Louisville.

Dr. Harkema also works with the NeuroRecovery Network (NRN). Its mission is to provide support for the development of specialized centers that provide standardized rehabilitation using activity-based therapy. Funded by the Centers for Disease Control and Prevention through a cooperative agreement with the Christopher Reeve Foundation, the NRN translates the latest scientific advances into effective, activity-based rehabilitation treatments. Initially, the NRN is focusing on locomotor training.

As an enthusiastic proponent of activity-based therapy, Dr. Harkema presented much of her own research focused on locomotor training. Locomotor training is one of the treatment modalities used in Mary Free Bed's Intense Therapy for Motor Recovery Program. In a locomotor training session, an individual is suspended in a harness over a treadmill while trained therapists move the legs to simulate walking. The results of her studies support the theory that fundamental mechanisms that control human locomotion may provide strategies that can be used by physical therapists for the rehabilitation of walking for patients after neurologic injury.

According to Dr. Harkema, neural retraining involves activation of the neuromuscular system below the level of spinal cord injury. Training needs to be task specific and repetitive; specific sensory cues are required. Dr. Harkema noted, "The human spinal cord can generate locomotor patterns in the absence of input from the brain when provided with specific and appropriate sensory information." The spinal cord can adapt and use a "new nervous system" to execute motor tasks.

“Properly and continuously challenging patients to achieve higher levels of performance is critical to recovery.”

“Properly and continuously challenging patients to achieve higher levels of performance is critical to recovery,” Dr. Harkema emphasized. “Therapists and technicians must know the phases of recovery and how to use progression strategies for each phase to optimize recovery and assist the patient on the road to recovery.”

Tim Lesch, lead physical therapist for the Intense Therapy for Motor Recovery Program at Mary Free Bed, is encouraged by the optimism of both Dr. Young and Dr. Harkema. “Doctors Young and Harkema offered hope as they spoke about the future of spinal cord injury research and recovery. Both experts support the need for intense therapy programs to drive central nervous system re-organization. There seems to be little debate that activity-based therapy will be a key ingredient involved in successful regeneration of the spinal cord.”

Prevention of Chronic Complications and Health and Wellness with SCI

Maria Reyes, MD, double board-certified in physical medicine and rehabilitation and in spinal cord injury medicine, presented both on chronic complication prevention and health and wellness with SCI. Dr. Reyes is on staff at the University of Washington Spinal Cord Injury Rehabilitation and Spina Bifida Clinics and provides inpatient care as an attending physician at the University of Washington Medical Center and Harborview Medical Center Inpatient Rehabilitation Units. Dr. Reyes has served as medical director for the UWMC Inpatient Rehabilitation Unit since 2006 and also serves as medical director and attending physician for the UWMC Rehabilitation Consultation Services.

Treatment goals for SCI rehabilitation, according to Dr. Reyes, include preventing and managing specific medical complications (e.g., pressure sores, contractures, autonomic dysreflexia, respiratory infections, blood clots, urinary tract infections), safely mobilizing patients as early as possible, facilitating early transfer from the acute care setting to the rehabilitation hospital, and maintaining or improving outcomes.

Dr. Reyes described the many challenges SCI patients face in obtaining medical care after their discharge from inpatient rehab. She noted that many individuals have a hard time finding primary care providers, and when they do find one, the provider may need to be educated about the unique health care needs of the patient with SCI. For example, many doctors’ offices and health care facilities aren’t wheelchair accessible or don’t have the proper equipment (height adjustable exam tables) or staff who can assist with transfers. In addition, there can be difficulties with getting to and from medical appointments if patients do not have access to proper transportation.

Despite these challenges, it’s important that SCI survivors receive preventive care services and screenings for conditions both related and unrelated to their spinal cord injury, such as cardiovascular disease, diabetes, cancer, obesity, high blood pressure, and depression. “Periodic health exams serve to prevent morbidity and mortality via screening for modifiable risk factors and early evidence of treatable disease,” Dr. Reyes said. “Individuals with disability are at greater risk for unique health conditions and experience them differently.”

“At Mary Free Bed, we’re committed to restoring and maintaining our patients’ overall health and wellness.”

“At Mary Free Bed, we’re committed to restoring and maintaining our patients’ overall health and wellness,” Dr. Ho said. “That’s why we offer a full continuum of care for our SCI patients, from inpatient rehab through lifetime

follow up care in our outpatient clinic. We periodically survey our patients to find out whether their needs are being met. And we have our SCI nurse care coordinators available to assist with questions or make referrals for additional services.”

Mary Free Bed Restoring Hope and Freedom for People with SCI

Geoff Newmyer’s experiences with Mary Free Bed’s SCI Program and the SCI Symposium encourage him when he thinks about what the future holds for those with spinal cord injuries. “I’ve seen people at Mary Free Bed who have gotten things back,” Geoff said.



Geoff Newmyer (left) with friend. Geoff is back in the woods enjoying the sport of hunting.

“The program makes a person twice as strong and helps regenerate things. The programs here at Mary Free Bed help people’s brains make the connection to get the body to do something.”

In the meantime, as research goes on and promising therapies are developed, Geoff continues with his own therapy and treatment and hopes that he will have the conditioning he needs for the day when he does stand up on his own. ■

SCI Resources

- W.M. Keck Center for Collaborative Neuroscience
<http://Keck.Rutgers.edu>
- CareCure Community
<http://Sci.Rutgers.edu/forum>
- NeuroRecovery Network
www.ChristopherReeve.org
- **Hear the SCI Symposium’s Patient Panel Discussion**
www.MaryFreeBed.com/SCIPatientPanel

A highlight of the Spinal Cord Injury Symposium was the SCI patient panel session. Comprised of former Mary Free Bed patients, spouses, and one employee, the panel’s members provided information regarding their respective injuries and experiences, and fielded questions from the audience.

Listen to this year’s panel members as they answer questions on everything from parenting to insurance to building barrier-free homes. Their stories show how they overcame multiple challenges and have gone on to live very full lives.

Ask the Doctor

*By Sam Ho, MD
Spinal Cord Injury Program
Medical Director*



We were very fortunate to have such highly-respected and widely-acclaimed speakers here for this year’s SCI Symposium. Their presentations on the latest in spinal cord injury research raised a number of questions that I will respond to in this issue.

How do I keep up with the latest developments in spinal cord injury research?

It can be very challenging to stay up-to-date on the latest breakthroughs in spinal cord injury care and research. Your Mary Free Bed Spinal Cord Injury Program team members are here for you and are always willing to assist you with questions. Feel free to e-mail us at SCIprogram@MaryFreeBed.com or call Amy Arends, our SCI nurse care coordinator, at 616.242.9216 or 800.528.8989.

For those of you who have access to the Internet, there are several Web sites we recommend. In addition to those listed under the *SCI Resources* section of this newsletter, information on spinal cord injury research may also be found on several Web sites, such as the Christopher & Dana Reeve Foundation, National Institutes of Health, National Rehabilitation Information Center, and The Miami Project to Cure Paralysis. Links to these Web sites are available on our Mary Free Bed Spinal Cord Injury Program Web site, which can be found by visiting www.MaryFreeBed.com and following this path: Spinal Cord Injury Program > Resources > Internet Links.

You can also set up an “alert” through your favorite computer search engine, such as Google. Google Alerts are e-mail updates to your personal e-mail address of the latest search results (Web, news, etc.) based on your choice of topic. You can tailor these alerts to help you monitor certain news items or keep current on events by entering keywords or phrases (e.g., spinal cord injury). It’s easy to do – just go to www.Google.com/Alerts and follow the instructions.

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How do I find information regarding clinical trials for people with spinal cord injuries?

The National Institutes of Health has a very comprehensive Web site that responds to multiple questions related to current clinical research and clinical trials. Go to their home page (www.NIH.gov) and click on the Clinical Trials heading. This will take you to a site that responds to several commonly-asked questions, such as: How does clinical research work? Who participates in clinical research? What do I need to know if I am thinking of participating? Where can I find a clinical trial? What happens after a clinical trial is completed? If you go to their "A to Z" listing of clinical trials and enter the phrase "spinal cord injury," you will see a registry of federally and privately supported clinical trials conducted in the United States and around the world. This site gives you information about each trial's purpose, who may participate, locations, and phone numbers. Clicking on the specific trial you are interested in will bring up that trial's Web page with detailed information.

What is important to know before participating in a clinical trial or research study?

First, it's important to know that participating in a legitimate clinical trial or research study is different from the "medical tourism" that Dr. Young referred to in his SCI Symposium presentation. There are many individuals around the world performing different types of medical procedures, including surgeries, that are not approved in the United States and are unsupported by true evidence-based research. Fees for these procedures vary widely, and most of them are quite expensive. Additional costs are involved with travel and lodging, taking time away from work, etc. Communication with non-English speaking health care professionals may be challenging, and hygiene and infection control standards in foreign hospitals may be sub-par. Your medical insurance is unlikely to cover any expenses associated with non-FDA approved procedures that are done outside of the United States – and this may include the cost of any later medical complications experienced as a result of those procedures.

Participation in true government approved clinical trials and research studies rarely involve fees for participants; in fact, most of them underwrite all of the costs for participation through grant funding. Participants are screened to see if they meet defined

eligibility criteria and are educated regarding all risks and benefits. Each participant signs an "informed consent" document, and can withdraw from the study at any time. Each clinical trial in the United States must be approved and monitored by an Institutional Review Board (IRB) to make sure that risks to participants are minimal and are worth any potential benefits. An IRB is an independent committee that consists of physicians, statisticians, and members of the medical community who ensure that clinical trials are ethical and that the rights of participants are protected. Federal regulation requires all institutions in the United States that conduct or support biomedical research involving people to have an IRB initially approve and periodically review the research. (National Institutes of Health: Clinical Research)

What can I do to be a good candidate for an upcoming clinical trial?

The best thing you can do is remain healthy, fit, and active. Different clinical trials have varying eligibility criteria in terms of level or type of spinal cord injury, time since injury, and age, among other factors. These factors may be out of your control; however, all researchers are looking for healthy subjects who will make optimal research candidates. The best way to be a good candidate is to do what's best for your overall health: stop smoking, limit or stop alcohol use, maintain a healthy diet and weight, exercise regularly, take the least amount of medication as recommended by your physician, and guard against the development of secondary complications (pressure sores, respiratory infections, urinary tract infections, to name a few.). ■

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SCI Peer Support Group

One of the best resources for people with spinal cord injuries is their peers. Join the Spinal Cord Injury Peer Support Group at Mary Free Bed. Meetings are held on the fourth Mondays of the months of January, April, July, and October at 6 p.m. in the 2nd floor conference room at Mary Free Bed. Please visit our web site at www.MaryFreeBed.com for more information.

Stay in Touch

Send your personal news and updates to:

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Event Information

Adaptive Downhill Ski Clinic

Saturday, January 31, 2009
(snow date: Saturday, February 7, 2009)
Cannonsburg Ski Resort, Cannonsburg

Adaptive Rock Climbing Clinic

Saturday, March 7, 2009
Grand Valley State University, Allendale

Adaptive Golf Clinic

June 2009 - *date to be announced*
Scott Lake Country Club, Comstock Park

Adaptive Water Ski Clinics

Friday, July 10, 2009 and
Friday, July 31, 2009
John Collins Park, Reeds Lake, East Grand Rapids

Adaptive Kayak Clinic

August 2009 - *date to be announced*
John Collins Park, Reeds Lake, East Grand Rapids

For additional information on these adaptive sports events, please visit our website at www.MaryFreeBed.com.

Participate in Online Survey

The Center for Assistive Technology & Environmental Access at Georgia Institute of Technology is currently seeking wheelchair users to participate in an online survey about the environmental barriers they confront as they go about their daily lives.

If you are interested in participating, please go to the following link:
www.SurveyGizmo.com/s/61438/Barriers-To-Wheeled-Mobility-Users-In-The-Community.

Your input will help researchers and policy makers better understand how physical barriers impact your participation in your communities.

Special Thanks

Special thanks to all of those who contributed to the success of this year's SCI Symposium, especially our SCI panelists, presenters, and vendors!!!

- Amy Arends, BSN, RN, CRRN, moderated the SCI panel discussion section. Participants were David Briggs, Shelly Loose, Kelly and Scott Merz, and Brad and Jen Prince.
- Charlie Hansknecht, PT; Tim Lesch, PT; Ashley McKnight, MS, OTR, ATC; Jim Vugteveen, MS, OTR; and Jackie Wondolowski, LMSW, presented on *Mary Free Bed's Spinal Cord Injury Program: Innovations and Outcomes*.



Begin your personal journey... What drives you to finish?

32nd Annual Fifth Third River Bank Run
Saturday, May 9, 2009 • Grand Rapids, Michigan

*Wheelchair and Handcycle Divisions are
sponsored by the Mary Free Bed Guild*

Information

For more information, please visit our website at www.MaryFreeBed.com/RiverBankRun.aspx. You may also contact Kelly Merz at 616.356.1861 or Kelly.Merz@MaryFreeBed.com.

Registration

Register online at www.53RiverBankRun.com to compete in the Wheelchair or Handcycle Division.

Spinal Cord Injury Program

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