"Our greatest strength is the peer-support model, and this is the value we bring to the program," states Jim Magyar, Executive Director of the Ann Arbor Center for Independent Living. He is reviewing the history of the University of Michigan Model Spinal Cord Injury Care System and its relationship with the Center. Partnership between the Center's community-based, independent-living approach to rehabilitation and the hospital-based, medical approach has been a hallmark of the U-M Model SCI System, since its inception in 1985.

"Collaborative programming actually began two or three years before that and formed a basis for the current relationship," Magyar continues. "In 2001, we celebrate 25 years of serving the community. We consider it a major accomplishment that we have written more than 15 years of our history in partnership with the U-M Model SCI System!"

During this time, four successful applications have been submitted to the National Institute on Disability and Rehabilitation Research for funding. The most recent award covers the years 2000-2005. The partnership caught the eye of the panel of rehabilitation and disability experts who reviewed several dozen applications. Reviewers repeatedly cited the U-M Model SCI System using such phrases as, "strong partnership with consumers and the independent-living community." They noted, "creating good linkages with community resources" and further praised the "involvement of individuals with spinal cord injury and other disabilities."

Tom Hoatlin, lead peer consultant for the partnership, is enthusiastic about going into the hospital to relate his experiences of living with a spinal cord injury for persons currently in rehabilitation. His paraplegia results from a gunshot wound about 10 years ago. "Face-to-face contact is important," he says. "What we do best is help with personal, emotional adjustment to a new life. People can look at me and see that I have a job, a marriage, and a child. They can see that I do everything I did before, only differently!"

In collaboration with Occupational Therapist Patty Zuba and Physical Therapist Cindy Douglas, Hoatlin facilitates the nationally known Hospital to Community Program. Included is a series of classes on health and wellness, personal-assistance management, travel, recreation, and advocacy. Other topics are employment and assistive technology, transportation, sexuality, housing, and communication skills. In addition, Hoatlin emphasizes the importance of one-on-one dialogue and engaging in question-and-answer sessions. One of the first questions people ask is, "How are you getting along with your bowel and bladder program? I'm nervous about it-how will it work when I get home?" Other questions focus on recreation, Hoatlin's favorite topic. Newly injured individuals wonder whether he can still participate in sports, such as water and snow skiing. (He does!)
Hoatlin finds that many people are eager to learn how to gain or maintain employment. "And they may ask me how I manage the marriage relationship," he says. "We encourage people to hire personal assistants. Relating to spouses or significant others and other family members should continue, without saddling these relationships with the responsibilities of a primary caregiver. This is especially important!" Hoatlin also addresses questions relating to intimacy, focusing on such concerns as positioning, fertility, and lack of spontaneity. Participants in the Hospital to Community Program with fertility questions are often referred to Dr. Dana Ohl of the U-M Division of Urology, or specialists in their own communities.

Peer Consultants Clark Shuler and Rick Baisden of the Center staff join Hoatlin in this work. They have 13 years' and more than 20 years' experience, respectively, in dealing with their spinal cord injuries. "The program allows us to model the leading of a life that is not overwhelmed by tragedy. People can see that when they look at us! In our disabilities, we simply reflect a part of human diversity."

Representatives from across the state received an orientation to the Hospital to Community Program, when Magyar presented information about this model at the staff retreat of the Michigan Association of Centers for Independent Living in Lansing in March. At the meeting, Hoatlin described peer-consulting support and advocacy activities.

Staff members of the Center also join U-M Model SCI System researchers to study the impact on employment of legislative and policy changes. This is of particular interest, since about three-fourths of the participants in the project, who are of working age, are not employed following injury. Many of them fear losing disability benefits if they do return to work. Another joint research effort focuses upon key factors that influence participation in various aspects of society, after injury.

Individuals frequently do not have questions for peer consultants until after discharge from the hospital. Issues may arise many months or even years later. Lifetime follow-up is not only the centerpiece of the U-M Model SCI System, it also fits well with the overall mission of the Center. For this reason, Magyar and Hoatlin encourage readers to call the Center at (734) 971-0277, with any concerns that you may have, regardless of the time that has passed since your spinal cord injury. Staff there can put you in touch with resources in your own communities, as appropriate. You are always welcome to call the U-M Model SCI System office for further information, (734) 763-0971.

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U-M Model SCI System Continues; Receives National Recognition

"We have received recognition and praise in Washington for our strong commitment to community-based programs, our alliance with the Ann Arbor Center for Independent Living, and our support from the University," reports Denise G. Tate, Ph.D, principal investigator and director of the project. She is speaking of the five-year grant that the U-
M Model SCI System has received, to continue research and demonstration of model care for individuals with spinal cord injuries. She emphasizes that University support comes not only from the Department of Physical Medicine & Rehabilitation, but also from the University of Michigan Hospitals & Health Centers and Larry Warren, their executive director.

This marks the fourth consecutive time since 1985 that the National Institute on Disability and Rehabilitation Research has awarded funding to designate the U-M Health System as a Model Spinal Cord Injury System. As a result of the latest competitive application process, former model systems in Chicago, Milwaukee, Cleveland and Detroit no longer receive funds, leaving the U-M the only such center available to injured persons in the Upper Midwest. Currently there are 16 model systems across the country, from southern Florida to Seattle, and from New England to California.

"We care about our patients and former patients, and we are extremely grateful for their support of our project activities throughout the years," says Dr. Tate, a psychologist who works with persons with spinal cord injury admitted to the U-M Health System. We especially appreciate their participating in our follow-up research studies and their responding to questionnaires about their physical and emotional well-being. Our goal is to ensure that research conducted by our center reflects personal priorities of persons with spinal cord injury. We want the knowledge we gain to be relevant to and utilized by those who we care the most about!"

One goal for the next five years is to ensure the continued availability of comprehensive services for persons admitted to the U-M Health System, from the time of their injury throughout lifetime follow-up care. Dr. Tate describes other goals. "We will continue to investigate critical issues through our collaborative projects with other model systems and in our own studies right here at the University of Michigan. "We will promote education and share the knowledge we gain with injured persons and their families and with professionals working in the field of rehabilitation and in other related areas."

Former patients, staff and peers of the Ann Arbor Center for Independent Living, and members of the SCI rehabilitation team joined project staff to identify areas of importance to study during the next five years.

These include:

- The influence of alcohol on recovery following motor vehicle crashes,
- effects on employment of recent legislation related to return to work,
- quality-of-life outcomes for injured older children and adults who are ventilator dependent, effects of the Wellness with SCI Program described elsewhere in this issue, and factors associated with community reintegration. To obtain long-term, follow up information related to needs, care, and survival with spinal cord injury, project staff will continue to contact former patients, regardless of how long ago they may have been injured. These research data contain no information that could identify any individual. The data are sent to the National SCI Statistical Center at the University of Alabama,
where they are combined with data from other Model SCI Systems.

WE WOULD LIKE TO HEAR FROM YOU! We invite you to contact us or pay us a visit. Full information about how to reach us is on the address panel. We welcome your questions and comments!

Schulte Sinks Winner; Helps US Capture Bronze

"The greatest ever!" exults former patient Paul Schulte, describing his experience at Paralympics 2000 last October, with Team USA, the men's wheelchair basketball team. To back up that remark, Schulte, who was a first-timer at the Games, had to rely on veteran teammates. They assured him that the accessibility, facilities, and hospitality, in Sidney, Australia, were superior to anything they had encountered previously. "We were treated like kings, like full-blown Olympic athletes!" Schulte exclaims.

At 22 and "the baby of the team," Schulte made a little history of his own, by lofting the winning shot as time expired in the bronze medal game with Great Britain. "More than 18,000 people saw that game," he says, "making it the largest crowd in history to watch a wheelchair basketball game. Of course, we had dreams of going all the way," he adds. "We were disappointed to be knocked out by the Netherlands, who then lost the gold to Canada by a wide margin. We felt we could have matched up better with Canada!"

Schulte, who received treatment at C. S. Mott Children's Hospital about 11 years ago for his spinal cord injury at the L-2 level, was featured last year in Profiles of Former Patients in SCI access. He attends the University of Texas.

Well-On-Wheels Rolls Out With Big W-O-W!

WOW! The initials say it all, and if you had been at the University of Michigan Hospital on a Friday in early April, you would understand why! That day saw the first group of 17 participants roll into a wellness workshop exclusively for people with spinal cord injury. Bright blue t-shirts, red and yellow balloons, cha-cha music at the break, eight enthusiastic workshop facilitators, 15 wheelchairs, two "Paws With a Cause" golden retrievers--all helped to set the scene. Soon there was a great deal of animated exchange among those present. Talk ranged from doing adapted downhill skiing in Colorado, to the freedom of snowmobiling during Michigan winters, to the value of herbal supplements, to the importance of respect for oneself as a lovable sexual being. Wow!

Well On Wheels (WOW!) is a six-session wellness workshop, which makes up the educational segment of a larger groundbreaking study called the Wellness with SCI Program. Sunny Roller, who coordinates the program, states that the purpose is to test the effectiveness of WOW! on the health and health behaviors of participants. Does a
wellness workshop make a difference?

The overall program lasts 8 months, beginning with a series of physical and knowledge assessments and measures of attitude for all participants to complete. Each attends three Saturday "Health-O-Rama" clinics to get a wellness check-up. Based on a random drawing at the first clinic, approximately half of the participants will attend the 6-part wellness workshop. The other half will not. This is to provide statistical validity when the findings of the program are analyzed.

WOW! is designed to help people take ownership of the wellness areas that directly impact the quality of their lives. Participants have various levels of injury. WOW! is highly interactive, to allow learning with experts more than from them. Workshop facilitators are committed to serve as participants' partners in wellness, not just as teachers of wellness strategies. Each WOW! session covers sexuality, lifestyle management (coping), physical activity, nutrition and preventing new health problems. Participants have two objectives-to understand the information presented and then to apply what they have learned, by developing personal everyday wellness strategies.

"The traditional focus upon overcoming the effects of spinal cord injury takes a person only partway to wellness," explains Denise Tate, Ph.D., director of the U-M Model SCI System and the principal investigator of this study. "Developing a proactive personal commitment to a wellness-focused lifestyle can improve health and quality of life!"

Measuring how much improvement can come as a result of the structured wellness workshop is one of the objectives of the Wellness with SCI Program.

The program is tracking two groups of participants. The first group of 33 started in March, and the second begins in June. Participants receive a $45.00 honorarium each time they come to University Hospital to help cover their time and parking and travel expenses. After attending a minimum of four sessions, each receives a personal arm ergometer to use for home exercise. Participants must meet these selection criteria:

between the ages of 18 and 65,
at least one year after injury,
injury at the C-4 neurological level or below, and
willing and able to participate over the 8-month span of the study.
To learn more about WOW! and the Wellness with SCI Program, contact Dr. Tate at our office, as shown on the address panel.

Lecturer Discusses Surgery to Improve Function in Upper Limbs

Emotional and functional needs of persons who have tetraplegia resulting from spinal cord injury were the focus when Dr. Vincent R. Hentz spoke recently at the University of Michigan Hospital. Dr. Hentz, of Stanford University Medical Center, described current developments in surgery to improve upper-extremity function. Goals of these tendon-
transfer procedures are to obtain or improve active elbow extension and a one-hand grip, keeping fingers pliable for human contact.

Dr. Hentz discussed the emotional impact and the importance of surgeons developing a lifelong relationship with their patients. He stressed the team approach to the reconstruction of the upper limb for these injured individuals. Who is the key person on the team? The injured person, fills that role, he declared, along with any attendant and family members. Leadership roles on this team shift from time to time. At one time, a therapist serving as a patient confidant, may head the group. At other times, a surgeon provides inspiration, or a physical-medicine physician (physiatrist), serves as leader, while advising and coordinating the rehabilitation program.

What is the ideal time for surgery? Probably this will be at least one year post-injury and may be many years later, depending upon the individual. Enough time must pass for injured persons to achieve neurological stability and feel they are ready, both emotionally and psychologically. In addition, surgery is related to the entire rehabilitation process, and the team develops a plan to determine which function to seek to restore first.

Who is a candidate for surgery? Persons who are motivated and flexible and open to new ways of functioning that may change how they have adapted to their injuries. They realize they must go through a period when they will actually lose function, immediately after surgery, before their function can improve. Even though they may have gotten along for years after injury without surgery, they are willing to trade a period of greater dependence, as they recover from surgery, for the promise of greater independence in the long run.

After identifying a potential candidate, the team evaluates the motor and sensory resources of the upper limb, as well as any structural and functional changes since injury. The team also considers the candidate's motivation and type and level of family support. Since surgery may cause a muscle to lose strength, a potential candidate must demonstrate motor strength of 4 or 5 in at least one muscle below the elbow, according to the American Spinal Injury Association's rating scale.

The team analyzes all of the characteristics of the individual's current grip and the unique needs of the hands. To be successful, surgery must significantly improve function, particularly with weight-bearing activities. One measure of improvement may be the individual's ability to independently put on and take off splints after surgery. Surgeons teach new methods of transfer and locomotion, so their patients do not cancel the effects of these procedures, by reverting to their old ways of functioning. Again, motivation is the key.

Extension of the elbow gets top priority when tendon transfers are a consideration. Next in importance are extension of the wrist, thumb pinch, and grasp and release of the fingers. Stabilizing elbows is more important than improving grip, since the lack of elbow extension reduces the environment by several hundred percent. This lack prevents pressure relief and limits the ability to propel a wheelchair.
Dr. Hentz has followed surgery patients for more than 10 years to study how long the surgery lasts. In one such group of 15 patients, most had complete injuries, and over half were currently able to use a manual wheelchair. Several indicated enormous improvement and could transfer themselves into and out of their wheelchairs. Dr. Hentz stressed the importance of long-term follow-up, noting that it is just as important to re-examine the function of the upper limb, as it is to regularly test kidney function.

Plastic Surgeon Dr. Kevin Chung, Director of the University of Michigan Hand Center, performs tendon transfers here. He praised Dr. Hentz for the cooperation and guidance offered by the Interdisciplinary Center at Stanford. Dr. Chung hopes this article "can raise awareness to allow us to identify good surgical candidates!" He is working closely with members of the rehabilitation team to do this.

If you are interested in learning more about these procedures, you may call the Hand Center, (734) 763-0971.

Annual Meeting on SCI Issues, Advances Comes To Northern Michigan

Staff of the U-M Model SCI System traveled north to Traverse City in early June to join health-care professionals from across the country for an annual conference on spinal cord injuries. The meeting spotlighted a multidisciplinary approach to today's clinical challenges. Sessions offered state-of-the-art treatment strategies, including the role of alternative medicine. Other presentations featured current research directions, pointing up advances in cure research.

Dr. Denise Tate, project director, discussed the way that depression and substance abuse issues affect rehabilitation. At another session, she presented results of studies on how to smooth the transition for people moving from rehabilitation back into the community. Steven Laux, a U-M graduate student in biomedical engineering, described the SCI survivor's perspective on high-tech assistance. Also attending these sessions were Physical Therapist Cindy Douglas and Occupational Therapist Patty Zuba.

RESEARCH HIGHLIGHTS

Employment Status of Persons with Traumatic SCI: A Qualitative and Quantitative Investigation

The initial quantitative phase of this study focused upon factors influencing return to work. Findings suggest that the most important predictors are level of education before injury, age, and functional status. Surprisingly, the type of work done prior to injury was not a major factor.
A second, qualitative phase gathered detailed life stories of several individuals to further examine the influences on return to work. Findings suggest that people who return to employment view work as playing a more important role in their lives. They feel compelled to maintain their pre-injury lifestyles, they are more optimistic overall, and they believe their employers' benefits are adequate.

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Hierarchical Linear Modeling of FIM Growth Curve Characteristics following SCI

The purpose of this study was to evaluate the extent of functional independence that people regain after spinal cord injury, as measured by the Functional Independence Measure (FIM). The study found that improvement in FIM scores ends before the first year following injury for most people. The study revealed considerable variation in the process of recovery, depending upon severity of injury. Those with the most severe impairments seemed to have little functional recovery, while there are no consistent trends among people with less severe impairments. This study casts light on how functional recovery, as measured by the FIM, changes over time.

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Enhancing Community Reintegration: A Model for Providing Independent Living (IL) Follow-Up Services

The U-M Model SCI System served as the lead center for this collaborative study with five other Model SCI Systems. Each model system partnered with a local Center for Independent Living (CIL) to offer a program of IL services after discharge. Purpose of the study was to measure and compare quality of life in a group of subjects who participated in this program of services and a group who did not.

It was expected that participants would obtain more IL services. They would be more active, would have a greater sense of control over their lives, and would feel they had a better overall quality of life than non-participants. This did not happen. On their own, non-participants actually obtained as many IL services as participants. The two groups did not differ in scores measuring quality of life. In a sense, these findings are good news! They suggest that IL services are widely available.

Unlike the strong partnership long enjoyed by the U-M Model SCI System and the Ann Arbor Center for Independent Living, as reported elsewhere in this issue, most of the collaborating Model SCI Systems and their CIL affiliates had had no previous relationships. They initially tended to experience difficulties in working with each other. One benefit of the study was that their communication improved over time.

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Accounts of survivors highlight this valuable resource for anyone interested in learning more about spinal cord injury. Written in a compelling manner that is easy to read, the book begins from a medical perspective, with an informative description of what to expect immediately following injury. The authors pay considerable attention to the complex emotional and psychosocial issues related to healthy adjustment after injury. These range from personal to family to functional concerns.

With details covering types of injuries, complications and other medical issues, the book is an excellent resource, both for survivors and also for those providing support and assistance. Additionally, the authors include an extensive discussion of research, focusing upon current efforts and indicating what might be expected in the future.