Spinal Cord Injury Researcher Named One of America’s Best

by Rosalie Karunas

“I firmly believe that we will develop treatment to restore function!” declares Dr. Wise Young who was recently cited by TIME Magazine as one of America’s Best in Science and Medicine for his research on spinal cord repair. While Dr. Young heads the Center for Collaborative Neuroscience of Rutgers University, he maintains close contact with staffs of the University of Michigan Model Spinal Cord Injury Care System and other Model SCI Systems across the country.

To update our earlier interview and as a follow-up to last summer’s article in TIME, we caught up with Dr. Young in October at his New Jersey research facility. Later in the month, he spoke with Project Director Denise G. Tate, Ph.D., at a national meeting of health care specialists in rehabilitation. They discussed new strategies and solutions in spinal cord injury therapies.

“I do not believe any single center will come up with a cure. Only the best scientists working together can produce this.” To that end, Dr. Young’s mission is to teach other centers how to conduct SCI research. Dr. Young encourages readers to become knowledgeable about the current status of research. About 150 laboratories utilize the resources he offers.

He suggests they access his Web site, “Care Cure Community,” (http://sciwire.com). Here, forums offer a good starting point for readers to find out the latest information on spinal cord injury care, research, and clinical trials. A list of clinical trials in spinal cord injury is constantly being updated. Dr. Young notes that new developments in these areas are usually posted within hours. He invites readers to register, so they can post questions and engage him in conversation.

“Of all of the technologies currently being developed, why are they not being applied to humans?” Dr. Young reports this is one of the questions most frequently raised in his forums. “Research with animal models allows us to develop the best treatment for humans,” he explains.

Many participants in his forums wonder if they should investigate overseas clinics offering experimental treatments. Dr. Young described work in Taiwan, Ecuador, and Russia. “These treatments supported walking on a treadmill to reverse the effects of non-use of the limbs following injury. Intense training of this type may restore locomotion.

Emerging therapies focus both on creating new nerve fibers to replace those destroyed by the injury and also on strengthening existing fibers that may have been damaged. Vaccines and electrical current have been found effective in stimulating regeneration in the spinal cord. Stem cell transplants are showing promise in restoring damaged fibers. Right now, there are about a dozen clinical trials aimed at stem cell transplants. “Even though only 10% of the nerve fibers may be healthy, they can support substantial function,” Dr. Young points out. “This may make a small but significant difference in a person’s overall functional ability.”
Former Patient Joins Olympic Torch Relay

by Rosalie Karunas

When the Salt Lake 2002 Olympic Torch Relay reaches southeastern Michigan in January, Travar Pettway joins torch runners of all ages in this relay to February’s Winter Games. The torch travels a total of 13,500 miles in its 65-day journey across America. Modes of transport include air, train, ship, dogsled, snowmobile, horse-drawn sleigh, and Travar’s power wheelchair with ventilator attached. Each torchbearer carries the flame approximately 0.2 miles, or about two city blocks.

Travar lost the ability to use his limbs and breathe on his own when he sustained a spinal cord injury from a gunshot wound to his neck seven years ago, at the age of 17. Determined to make the most of his life, Travar is currently a history major at Eastern Michigan University. He has his eye on law school and a life of public service. He speaks nationally on gun control and the effects of teenage violence, encouraging young men and women to strive for their goals.

Travar is a member of the Advisory Council of the University of Michigan Model Spinal Cord Injury Care System. He also serves on the Boards of Directors for the Ann Arbor Center for Independent Living and for Trail’s Edge, a camp for ventilator-dependent children. These responsibilities allow him to see “what goes into decision-making in programs that serve people with disabilities. I hope I have influenced some of those decisions in a positive way.” Recently, he organized a young-adult weekend for peer counselors and former campers of Trail’s Edge.

Travar has developed a Web site, “Disability Dramas,” seeking to shed new light on the perception of people with disabilities. He feels they are often weakly portrayed in the movies. He takes on the challenge of showing these individuals as role models—strong, intelligent, and tough, by featuring stories of their determination, triumph, and courage. The site includes links and a chat room, and he welcomes input from our readers. You will find the site at www.disabilitydramas.com.

In recognition of Travar’s remarkable and inspiring story of Olympic spirit, Chevrolet has named him an Olympic Torchbearer. Tom Hoatlin, peer consultant of the U-M Model SCI System, nominated him for the honor.

“Paralyzed from the neck down is better than being paralyzed from the neck up,” Travar points out. “I hope my participation in the torch relay will show that people with disabilities have proven their worth and declared a place in society. I’m honored to be part of something that has such a rich and important history!”

Travar Pettway will carry Olympic torch

What’s Happening on the Web?

by Martin Forchheimer

There are hundreds of Web sites that can be of interest to people with SCI, their family members, and rehabilitation professionals. Three of them are briefly reviewed below.

Our Web site, www.med.umich.edu/pmr/model_sci/, has been upgraded during the last several months. One noteworthy enhancement is that all versions of our newsletter dating back to Fall 1997 are now on line. Another enrichment is that a bibliography of manuscripts and presentations made by the staff of the U-M Model System is now on line, sorted by topical area. This will continue to be updated, and you can look forward to finding other improvements on this site in the near future.

The Institute on Independent Living’s site, www.independentliving.org/, is a rich resource of information and training materials on numerous topics related to independent living. Examples of areas covered are personal assistance, technical assistance, peer support, and advocacy. The Institute’s site contains 30 discussion groups on a variety of topics, and a library of several thousand articles, both written for this site and previously published in peer and non-peer-reviewed journals.

The Foundation for Spinal Cord Injury Prevention, Care & Cure site, http://fscip.org, includes a wealth of information on a variety of topics, ranging from recent research efforts on care, cure and prevention, to financing and managing disability-related expenses, practical care information, to links to SCI institutions, medical facilities, and government agencies. The Foundation’s site also provides a list of professionals who have volunteered to provide limited legal, financial, medical, and aquatic safety advice. All of these consultants are Michigan residents.
Staying well is fun and important. A balanced way to approach wellness is to focus on three areas: nutrition, physical activity and lifestyle management. Here are some things to try. You can adapt them to your own needs, do them indoors and practice them all winter!

**Nutrition**
Try the three P’s of holiday parties. **Plan** ahead and eat less a few days prior to a party. **Prepare** a small sandwich or low calorie snack to eat before going to the party so you won’t be starving. **Picture** yourself healthier and happier when you aren’t stuffed or haven’t put on extra weight.

**Easy Recipe: Cola Chicken**
4 boneless skinned chicken breasts
1 12 oz. can diet cola
1 cup catsup
Place chicken in frying pan. Add cola and catsup. Simmer 1 hour covered. Remove cover last 20 minutes to reduce liquid. Salt and pepper to taste. Serves 2-4. Enjoy!

**Physical Activity**
People with SCI have an increased risk for cardiovascular disease. It’s important to increase activity, decrease fat intake in the diet, and limit or eliminate alcohol use and cigarette smoking. Exercise increases muscle mass. Since using muscle burns many calories, increasing your muscle mass means more of your food will be used to keep those muscles running, decreasing excess fat and body weight.

Try this exercise for shoulder strengthening to help with lifting and transfers:
• Tie stretch band to doorknob.
• Turn wheelchair so that it is parallel with the closed door at least arm’s width distance from door.
• Hold on to or wrap stretch band around wrist that is closest to door.
• Pull band down towards chair, elbow straight, keeping thumb facing the body. Do not raise arm above shoulder height.
• Repeat 10-20 repetitions and perform 2 more sets (or whatever you can do without pain.)

**Lifestyle Management**
Everyone needs help these days managing stress. Living with SCI brings its own unique stresses. Relaxation exercises reverse the negative effects of stress on the body and mind.

Try this relaxation exercise:
• Sit with spine erect, eyes closed or half-open, hands in lap or on thighs.
• Take 3 deep cleansing breaths. Inhale through the nose and exhale through the mouth.
• Be aware of breath. Thoughts and sensations will come. Acknowledge them. Label them (such as thinking, feeling) and gently return your attention to the breath. This is a practice in letting go.
• Begin with 5-10 minutes per day and slowly extend the duration over time.

Based on Well-On-Wheels Participants’ Manual

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**Ask the Physician**

Anthony Chiodo, M.D., a physiatrist at University Hospital who specializes in treating patients with SCI, answers readers’ medical questions.

1. **Question:** I have a cervical spine injury. Is there any way for me to lie down without pain?
   **Answer:** Yes! Your position in bed and your bed and pillow interact to allow you to achieve this state. Providing proper support to the neck and head in a lying position is important. If you lie on your back, a thin pillow is best; if you lie on your side, a thicker and denser pillow is needed to provide support. This will, of course, depend on your individual anatomy, cervical surgery history, and sleeping habits.

2. **Question:** I was having trouble with bladder infections. A doctor prescribed mandelamine, which has worked very well, and I rarely have these infections now. What is it and how does it work?
   **Answer:** Mandelamine is a compound that is concentrated in the bladder. In the presence of acidic urine (low pH), the medication converts to formaldehyde which kills bacteria. It is a useful way to prevent infections if urinary acidification does not work well enough. Since mandelamine is not an antibiotic, it does not leave you vulnerable to resistant strain infections.

3. **Question:** What is hydronephrosis? A urologist told me that one can show signs of this in the kidneys, but there is no need to worry about it. Is this true?
   **Answer:** Hydronephrosis is an enlargement of the ureters and the urine collecting system in the kidneys. It is a sign of obstruction by a stone or by a high pressure bladder which is most common in patients with SCI. These issues need to be evaluated before knowing if hydronephrosis is benign or is a sign of serious or impending kidney disease. If a thorough medical evaluation showed no other abnormality, you would not have to worry about hydronephrosis.

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*This new column in SCI access is established to help answer our readers' important health-related questions. If you have non-urgent questions for a physician or a psychologist who specializes in SCI, please contact our office.*
Early this year, Denise Tate, Ph.D. and colleagues began a research project called The Effects of a Holistic Health Promotion Program on Persons with SCI. The project, funded by the University, looks at the impact of a wellness program on persons with spinal cord injury. All participants take part in a series of health-o-rama-type clinical evaluations, where they are tested at different stations around University Hospital for things like weight, endurance, and blood lipid levels. In addition, participants fill out questionnaires about their experience with new health problems, stress and activity levels, and their knowledge of good wellness practices.

Half of the participants attend a series of six wellness workshops called Well-On-Wheels! (W-O-W!) covering topics in nutrition, physical activity and lifestyle management. W-O-W! focuses on how to prevent new health problems. The intent is to provide the information, tools and incentives necessary to improve long-term health which would in turn improve a person’s long-term quality of life.

The first two groups of participants have completed the initial stages of this project. Here is what we know so far:

- 71% are male, 29% female
- average age is 43.5 years (range: 20-70)
- Spinal injuries range from:
  - C4/5 to L4/5 (44% to the cervical spine, 50% to the thoracic spine and 6% to the lumbar spine);
  - 44% are tetraplegics, 56% are paraplegics;
  - 46% have complete injuries and 54% have incomplete injuries.
- Average number of years since injury is 13 (range: 1-49); the median is 8.

At the beginning of the study, the most common problems reported by participants were urinary tract infections, followed closely by bladder and spasticity problems. Bowel problems, pressure sores, and respiratory problems were reported less frequently.

An early look at the data collected from the workshop and comparison groups prior to and two weeks following the workshop show some positive trends regarding the impact of the workshops on participants’ knowledge acquisition, perceived abilities and their health behaviors. In a pre-test for knowledge about nutrition, physical activity and stress reduction, workshop and comparison groups scored 69% correct. Following the workshops, the comparison group remained at 69% while the workshop group improved to 81%.

With regard to current health behaviors, the comparison group has shown little change. The workshop group showed larger positive changes in ten of 15 factors (such as increasing consumption of high fiber foods, fruits and vegetables; decreasing consumption of foods high in fat and cholesterol; and exercising vigorously for 20 minutes at least three times per week). When asked about their ability to make positive changes in these areas, individuals in the workshop group showed positive increases after the workshops. One man revealed, “I had become very lazy in many of my personal attitudes. Participation in this program has helped pull me out of my rut.”

Participants evaluated their experience at the workshop as very positive. Nearly all rated the program as “extremely useful,” “extremely easy” to understand, and said they would recommend it to others “without hesitation.”

While these results are introductory, some of the early trends with regard to the effects of the workshops are promising, and the positive responses from participants about the value of the workshops are encouraging.
Marva’s Story: A Glimpse at Life After Spinal Cord Injury

by Claire Kulpakjian

In 1975, Marva Ways, her brother, and her two young children, Eddie Lee and LaTronda, were driving from Michigan to California. Between Iowa and Nebraska, on US-80, road construction and a puddle dramatically changed the course of Marva’s life. Her son, Eddie Lee, died in the accident and Marva sustained a spinal cord injury.

With characteristic warmth and wisdom, Marva graciously shares the story of her life after spinal cord injury and likens it to a book with unfolding chapters.

Chapter 1: Facing Reality

“I had to get a grip fast and face the depths of this new reality. My daughter needed me and this helped me to survive.” Her single-minded devotion to the welfare of her child transcended what concern she had for herself as she faced her SCI. “Facing the reality of the spinal cord injury was not a huge struggle because LaTronda needed me and that was my primary concern.”

Chapter 2: The Road to Recovery

Marva says, “I knew I’d never walk again, but the important thing was to get home. Because of my faith, my perspective became more important than my body.” Her strong faith in God was a stabilizing force, but her belief was tested. “I asked, why would the Lord take my son and let this happen to me? Then I realized that everything happens for a reason.”

Chapter 3: Healing and Dealing

When Marva returned to Detroit, life changed. The trajectory of LaTronda’s life had changed as well. A sensitive and caring child, LaTronda began helping her mother in daily life activities. When attendant care fell through, LaTronda became her mother’s primary caregiver. She wrote checks, even drove the van when necessary. Mother and daughter learned to take care of each other and together shaped a new life. “We became even closer than before. We would talk for hours and encourage each other.” Marva adds, “The Lord gifted my daughter with the maturity to accept our situation.”

Chapter 4: Getting back to Normal

Life went on. Marva was a typical mom with an energetic, bright teenager. Cheerleading, travelling, and beauty pageants rounded out their active life. “The wheelchair didn’t keep us from doing what we wanted to do. We just enjoyed life.” LaTronda’s friends didn’t notice Marva’s wheelchair much. She was simply a mother – the chauffeur, hostess, and cheerleader herself.

Chapter 5: Life Continues

Entering her fifth decade, Marva continues to live a full life. LaTronda is married now, with three young sons of her own. Marva delights in her grandchildren, watching them grow into young men. LaTronda is a social worker, working with families who are struggling through tough times—something she knows intimately.

Marva wonders if their experience together shaped a caring child into an adult who devotes herself to the welfare of others.

Marva says she now thinks more of growing older. “As I get older, I am not as strong as I used to be. Things are changing, so I try to prepare for the future.” She imagines herself on the proverbial porch, reflecting on a life well-lived, not in spite of her spinal cord injury, but because of it.

Marva is currently an active member of the Model SCI System’s Advisory Council and an enthusiastic participant in the Wellness with SCI Program at the University of Michigan. She is also a private consultant and disability activist. As her story continues to unfold, Marva reflects, “My life is much larger than my spinal cord injury. The injury keeps me grounded, but does not define me. I’ve done more with my life than I might have, had this not happened.”

“An inexhaustible good nature is one of the most precious gifts of heaven, spreading itself like oil over the troubled sea of thought, and keeping the mind smooth and equable in the roughest weather.”

–Washington Irving
The University of Michigan Model Spinal Cord Injury Care System publishes SCI access twice annually. This newsletter is designed to provide information on research, treatment, and social issues related to rehabilitative care, spinal cord injury, and disability.

Established in 1985, the U-M Model SCI System receives funding from the National Institute on Disability and Rehabilitation Research (Award #H133N00009). It is one of 16 Model SCI Systems in the United States. The purpose of this research and demonstration project is to improve outcomes of medical and rehabilitative care provided to individuals with spinal cord injury. Denise G. Tate, Ph.D., is the principal investigator and director. Further information is available on the World Wide Web.

SCI access is available free of charge by contacting the project at the following address:

University of Michigan
Model Spinal Cord Injury Care System
300 North Ingalls
Ann Arbor, Michigan 48109-0491

Telephone: (734) 763-0971
Fax: (734) 936-5492
E-mail: model.sci@umich.edu.
Web: www.med.umich.edu/pmr/model_sci/

Please notify our office if you have address additions or corrections.

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175 Guests Celebrate AACIL’s Silver Anniversary

by Claire Kalpakjian

On September 28, 2001, the Ann Arbor Center for Independent Living (AACIL) celebrated its 25th anniversary with a candlelit evening, gourmet food, touching tributes and frank hilarity at the Michigan Union ballroom. Supporters from the Ann Arbor community including the U-M Model SCI Care System enjoyed the wit of Tim Harrington, Executive Director of the Ability Center in Toledo, Ohio who was the master of ceremonies. James Magyar, AACIL Executive Director, and Jack Butler, President of the AACIL Board of Directors, presented special Founders Spirit Awards to Rick Weir, and honored John Weir and Corki McCorkle. John Kemp, President and CEO of Half the Planet Foundation gave the keynote address, entitled “Disability Culture: Perspectives on our Future.” His humor and deep understanding of the independent living spirit were a highlight of the evening. VSA arts of Michigan presented “Art Odyssey 2001,” a display of local artwork by people with disabilities which added an imaginative glint to the evening’s festivities.

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A Pledge of Support from the Ann Arbor Center for Independent Living

During the AACIL Silver Anniversary Gala, the heroes and victims of the World Trade Center disaster were honored and recognized through monetary donations taken for the New York Centers for Independent Living that were directly affected. It is estimated that an additional 2,500 people acquired disabilities in the wake of this tragedy. The disability community collectively mourns those who were lost and pledges support to those who remain.

—Tom Hoatlin, Director of Development, Ann Arbor Center for Independent Living

This newsletter may be accessed in two alternate formats: audiotape and large print. To request these versions, please call or write our office.