Don Anderson: Part of the Solution

by Kathy Klykylo

Don Anderson was in junior high school in 1968 when he dived into a gravel pit and broke his neck. He survived, but he was paralyzed with a spinal cord injury. In the pre-halo splint days, he spent four months in a circle bed.

A self-described “jock” with “all the nasty prejudices against people with disabilities,” Don had played football and other sports. Very self-conscious about his disability and emaciated appearance, he only went out at night. After several summers in a rehabilitation hospital, he was told he would probably never have a full-time job or a quality life. Even though Don’s dream of graduating with his high school class was realized, he was socially isolated and very depressed.

At Lansing Community College, Don asserted himself and asked strangers to sign his petition to be on the ballot for student government. There were ten open seats and he came in eleventh. But one of the elected students transferred to another school, so Don got the last seat. While in school, he worked with issues of accessibility at the college and community level, and attended the White House Conference on Needs of People with Disabilities in 1974. Though he didn’t know it, this was the beginning of his career in disability advocacy.

After graduation, Don lived at home with his parents, where he painted and wrote. Although life was comfortable, he wondered, “What about ten years from now? Will I have to live in a nursing home?” Even with a graduate degree in counseling, he felt he was doing what he could do, not what he really wanted to do.

In 1983, fifteen years after Don’s accident, two things changed the direction of his life. His mother died and he received a settlement from his diving accident, which provided a financial cushion for him. After a successful but unsatisfying job as a stockbroker, Don realized the work he had most enjoyed was in disability politics. “By this time I had learned about stigma and about internalized oppression. To refuse to do work for the disability community out of some false sense of pride would be untrue to myself.” In 1992 he went to the Ann Arbor Center for Independent Living and witnessed the Americans with Disabilities Act (ADA) coming into its own.

After five years at the AACIL, Don worked at Wayne State University in Services for Students

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A clinical trial is a research study to answer specific questions about vaccines, new therapies, or new ways of using known treatments. Clinical trials (also called medical research and research studies) are used to determine whether new drugs or treatments are both safe and effective. Carefully conducted clinical trials are the fastest and safest way to find treatments that work in people. Participants in clinical trials can play a more active role in their own health care, gain access to new research treatments before they are widely available, and help others by contributing to medical research. We are excited to report that the University of Michigan Model Spinal Cord Injury Care System (UMMSCICS) is currently participating in two pharmaceutical clinical trials as part of ongoing collaborations with other SCI centers across the nation.

Fampridine-SR in Incomplete SCI

This study is sponsored by Acorda Therapeutics, Inc., and it evaluates the safety and benefits of oral Fampridine-SR in persons with moderate to severe spasticity resulting from chronic, incomplete spinal cord injury. Fampridine has been shown to improve neurological function in animals and in people with multiple sclerosis or incomplete spinal cord injury. Specifically, previous clinical trials with Fampridine have shown improvements in spasticity, neurogenic pain, motor and sensory function, sexual function, and bowel and bladder function.

Specifically, participants must be between the ages of 18 and 70 years old, have an incomplete spinal cord injury between C4 and T10 for at least 18 months, and have moderate to severe spasticity present in four specific muscle groups below the waist.

Viagra® in Women with SCI:

The other pharmaceutical trial in which the UMMSCICS is involved is sponsored by Pfizer, Inc., and is targeted at women with a history of traumatic spinal cord injury who have difficulty becoming sexually aroused. Specifically, the purpose of this study is to evaluate the safety and tolerance of oral Viagra®. Oral Viagra® selectively blocks enzymes in the clitoris (or penis, in men) responsible for reducing vascular engorgement, thereby allowing sustained pelvic congestion and clitoral engorgement during sexual stimulation. These combined effects have been shown to increase vaginal lubrication and sexual responsiveness in able-bodied women in previous trials with Viagra®. A small, preliminary study using Viagra® in women with spinal cord injury demonstrated improved sexual arousal and a trend towards increased pelvic blood flow when compared to placebo.

Women included in this clinical trial must be at least 18 years old, have had a traumatic spinal cord injury at least 12 months prior to participation, and must be diagnosed with Female Sexual Arousal Disorder.

As opportunities allow, we anticipate becoming involved in additional pharmaceutical trials. Readers are encouraged to visit our website (www.med.umich.edu/pmr/model_sci/) for updates on these and other clinical trials soon to be available for participation. Additional information about the current UMMSCICS projects is available at this site, as well as updates on our clinical care continuum, lecture series, and links to SCI-related information sites. Happy browsing!

Send Us Your Story

The Model SCI Care System is looking for stories about the lives of people with spinal cord injuries for upcoming issues of our newsletter and for our website. We are interested in stories about diverse people of all ages and with all types of life histories. For more information, contact Kathy Klykylo at (734) 763-0971 or klykylo@umich.edu.
Dr. Chiodo, who specializes in Spinal Cord Injury Medicine, welcomes your questions.

This column was established to answer our readers’ important health-related questions. If you have non-urgent questions for a physician or psychologist who specializes in SCI, please contact our office.

**Question 1**

I recently had a cervical spinal cord injury and learned as an inpatient about autonomic dysreflexia. What should I do if I become symptomatic? Are hospitals and clinics familiar with autonomic dysreflexia and how they should treat it?

**Answer:** With regard to autonomic dysreflexia, the key is to treat any negative input that could be creating the problem: a full bladder or bowel, skin pressure, etc. If this does not work, it could be a serious situation if the blood pressure is too high and should be considered an emergency, especially with persistent headache. Medical attention is needed. The concern with emergency rooms is real, and if you live in a more remote area or are going to be traveling, it would be good to carry some information about the condition with you. It is easy to treat on an emergency basis. If the symptoms are fairly regular, medications are effective in reducing the frequency and severity of events.

**Question 2**

I have a constant worry of neuropathy in my elbows from the continuous weightbearing they endure from stabilizing a quadriplegic body that doesn’t like to remain in one place. Can you tell me what the symptoms of neuropathy are, and, more importantly, can you offer suggestions for preventing it?

**Answer:** The symptoms of neuropathy include numbness and weakness in the distribution of the compressed nerve. The way to avoid neuropathy would be positioning to avoid pressure on the nerve.

**Question 3**

At the time of my (cervical) injury, I was presented with three options for bladder management—self-cath, condom cath, and suprapubic cath. It is my impression that, depending on which or how many “professionals” one speaks with, there are valid arguments for each option. It ultimately boils down to the patient’s choice, but what is your bladder management option of choice and why?

**Answer:** The preferred method of bladder management is one that maintains normal bladder function. This involves maintaining bladder compliance, its ability to change volume without changing pressure. To do this, the bladder cannot become too small or contracted and cannot become too hypertrophied or thick-walled. Therefore, intermittent catheterization is the best method. Of course, there are situations where this may not be possible and other methods need to be chosen. These are the patient’s choice but it must be clear that the choice must include awareness of the distinct limitations and risk of the other methods which include sphincterotomy with condom catheter, suprapubic tube, Mitrofanoff Procedure, and others. These techniques generally trade controlling incontinence with bladder compliance and the potential need for future surgical treatment to correct long term complications of the surgical treatments mentioned.
Are you a part of the UM Model SCI Care System follow-up study? Have you ever wondered what we do with all the information from the questions we ask when we call you every few years?

First of all, we again want to say a very heartfelt “thank you!” to our readers who have agreed to participate in this long-term study of people with spinal cord injuries. We appreciate your commitment to this research. The UM Model System began collecting follow-up information in 1985, and some of you have been involved with this project since then. Since 1985, we have collected data on over 800 people with new, traumatic SCI who have been admitted to the UM Health System. Your participation in this follow-up helps us to further develop and strengthen our service system. The information we collect from you also allows us to develop and evaluate new methods to address the needs of people with SCI. Improved services can benefit you as well as others with injuries in the future. You are not identified in any report resulting from our follow-up.

In addition to maintaining our own confidential database, we combine our data with that of the other 16 Model SCI Care Systems across the country in a confidential database at the National Spinal Cord Injury Statistical Center, located at the University of Alabama at Birmingham. This larger database provides an even richer source of information for UM and other centers conducting spinal cord injury research.

The UM Model SCI Care System currently has five site-specific research projects and two projects that it is conducting in collaboration with other model systems. Information from the questions we ask you over the years make these and other studies possible. For more information on model system research, please go to our website and click on “research”: www.med.umich.edu/pmr/model_sci

Current Site-Specific Projects
- The Effect of Alcohol Use and Dependency on Spinal Cord Injury
- Predictors of Health and Quality of Life for Persons with Ventilator Assistance after SCI
- Health Promotion and Wellness: Application of Principles to Persons with Spinal Cord Injuries
- Strategies to Enhance Employment Following SCI: Knowledge and Impact of Public Policy Changes on Employment
- Determinants of Societal Participation Following Spinal Cord Injury

Current Projects Conducted in Collaboration with Other Model Systems
- Lifetime Outcomes and Needs: Refining the Understanding of Aging with Spinal Cord Injury
- The Effect of Managed Care on Rehabilitation Services and Outcomes for Persons with Spinal Cord Injury

This newsletter may be accessed in two alternate formats: audiotape and large print. To request these versions, please call or write our office.
A Women’s Guide to Coping with Disability
Resources for Rehabilitation, Lexington, MA, 2000

by Barbara Schoen

Women with disabilities face unique challenges. Traditional medical models often overlook issues directly related to women including sexuality, pregnancy, vocational goals, and most importantly, managing the multiple roles society places on the female population. This book gives credibility to women’s needs and provides resources for setting realistic goals, finding health-care providers who are knowledgeable and caring, working with rehabilitation professionals, and learning from other women with disabilities.

An excellent resource for women trying to achieve or maximize control of their lives, this book provides cost-effective and free resources, often with simple solutions to complex problems. Each chapter provides introductory and narrative information about national organizations and pertinent links to publications and tapes. In this age of instant information the magnitude of available materials and resources can be overwhelming. This book provides specific, current, and applicable resources.

A critical aspect of this publication is its ability to provide and communicate specific examples and tools supporting the empowerment of women with disabilities. This book discusses research which finds that women, who are unable to perform within traditional roles, are able to explore other opportunities and often maximize their potential. In addition, a disability may provide women access to education through the vocational rehabilitation system that they would not have had otherwise.

Equally important is the psychosocial response to disability. Statistics and research discussed in the book indicate that depression is a real concern for women with disabilities. On a positive note, there is empirical evidence that individuals who become disabled go through different psychological stages, usually resulting in acceptance and adaptation. These stages take time, and the power of self-help groups should not be discounted. They can help you learn and develop coping strategies to acquire a sense of control of your life. They can also help combat isolation and alienation and develop information networks. In addition, by helping others, a woman’s own positive self-esteem can be improved.
UM Model SCI Care System Brochure is Now on the Web!

If you want to learn more about the clinical services at the UM Model SCI Care System, visit www.med.umich.edu/prmr/model_sci/brochure.htm

This site provides detailed information about our continuum of care and more.

Michael Harris, Legislative Director of Paralyzed Veterans of America Michigan Chapter provided the following two websites of interest to travelers:

New Guide Helps Drivers Find Accessible Gas Stations
www.ican.com/channels/auto/pg/mimap.cfm

Drivers with disabilities can now find on the Internet a directory of accessible gas stations throughout Michigan.

Website Highlights Toll-Free Hotline for Air Travelers with Disabilities
airconsumer.ost.dot.gov/hotline.htm

The U.S. Department of Transportation (DOT) has established a toll-free hotline to assist travelers with disabilities.

The hotline provides general information to consumers about the rights of air travelers with disabilities, responds to requests for printed consumer information, and assists air travelers with time-sensitive disability-related issues that need to be addressed in “real time.”

Two websites sent by Sue Probert of the Ann Arbor Center for Independent Living:

GovBenefits
www.govbenefits.gov

GovBenefits is a partnership of many federal agencies and organizations with a shared vision—to provide improved, personalized access to government assistance programs. The list is expanded on a regular basis with the goal of eventually providing information for all government assistance programs.

Equipment Connection Online
www.comnet.org/kenny/eq_index.html

Equipment Connection Online is a program that “connects” buyers and sellers of used adaptive equipment. Whether you’re looking to buy or sell a wheelchair, motorized cart (scooter), walker, or van lift, Equipment Connection Online reaches your targeted audience.

From Rosalie Karunas, UM Model SCI Care System Advisory Council Member, and former Model System Staff:

Go the Distance
www.gothedistancedoc.com

This website features the award-winning feature film, Go the Distance—a documentary of a cross-country van trip of two friends, one of which is paralyzed and in a wheelchair. This video is much more than what you expect and well worth the small price. To order by phone, call (800) 228-4630.

Would you like to receive upcoming issues of SCI access online?

Just send the words “SCI access online” in the message line to klykylo@umich.edu.

Help us to streamline and reduce our costs!
Although life was comfortable, he wondered, “What about ten years from now? Will I have to live in a nursing home?”

with Disabilities, then recently came to Eastern Michigan University’s Access Services Office. Don likes the university environment because “It allows an aging radical like myself to be rewarded for stirring up trouble!” He thinks about the totally different society we will have in the future as an aging baby-boom population struggles with disability issues. He believes involvement with college students today will impact the world twenty years from now.

Don has two sons—“great kids”—ages 18 and 14, several good friends, and a sister in Lansing with whom he remains very close. He still writes; is involved in local, state, and national politics; and chairs the UM Model SCI Advisory Council. He is also working on a business plan for a resort/spa/conference center in the Caribbean for people with disabilities and their families.

As a young man, Don’s biggest challenge was to get past internalized stigma about his disability. Today his challenges are living with the uncertainty of funding for persons with disabilities and dealing with day-to-day life with a disability. But Don says, “I have had fun and have been able to do an amazing number of things. I am driven by the John F. Kennedy ethos, ‘If you are not part of the solution, you are part of the problem.’ I have met and worked with so many cool people—like Justin Dart, Ed Roberts, and Judy Heumann. And I have been able to play a small role in making this a more accessible society.” This exemplifies Don’s modesty about his accomplishments as a true public servant. He has been, and continues to be, part of the solution.


We are saddened by the death of James J. Peters, Executive Director of the Eastern Paralyzed Veterans Association (EPVA) in Jackson Heights, New York, on Friday, September 6, 2002, at age 57.

Mr. Peters devoted his life’s work to the improvement of health care for spinal cord injured veterans. On the national level, he worked to have spinal cord medicine designated an official sub-specialty by the American Board of Physical Medicine and Rehabilitation. He was instrumental in revitalizing the American Paraplegia Society, the national organization of physicians who provide care to persons with spinal cord injury.

Peters had a passionate commitment to spinal cord research, and during his tenure at EPVA, the Association provided $4.6 million to fund projects through Paralyzed Veterans of America’s Spinal Cord Research Foundation.

Peters was the recipient of many public honors and provided service on many national and local bodies involved in veterans and spinal cord health care. His passing is a loss to all of us in the SCI community.

“Exercise is for Every Body”

James Rimmer, Ph.D. visits Model System

by Kathy Klykylo

“Exercise is for Every Body.” This is the message delivered by James Rimmer, Ph.D., Director of the Center on Health Promotion Research for Persons with Disabilities at the University of Chicago. Exercise is important for everyone, but especially so for those with a disability such as spinal cord injury. People with SCI are at more risk than the general population for diseases such as diabetes, osteoporosis, obesity and heart disease, and aerobic and weight-bearing exercise are very important activities in managing these conditions.

Rimmer also reviewed the website of his Center on Health Promotion Research for Persons with Disability (www.ncpad.org). This site is a practical source for exercise, recreation, and fitness options for persons with disabilities.

For more information, call (800) 900-8086 (voice and TTY) Monday-Friday, 8:00-5:00 CST or go to the NCPAD website.
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 UM 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.

David R. Gater, M.D., Ph.D., Medical Director, Co-Director, Co-Principal Investigator
Denise G. Tate, Ph.D., Co-Director, Co-Principal Investigator

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/prmr/model_sci/

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

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Editor: Kathy Klykylo

Are you a woman with a spinal cord injury?

The UM’s Department of Physical Medicine and Rehabilitation and the Rehabilitation Institute of Michigan are launching a new study titled “Stress and Coping Over the Life Course: A Perspective on Women with Spinal Cord Injury.”

You can participate if you:
1. are 18 years of age or older
2. have no other major physical disabilities
3. have no reasoning deficits that would hinder completing a two-hour, in-depth interview
4. are able to read, write, and speak English
5. live in a non-institutionalized setting

For more information, call Sunny Roller at UM (734) 936-9474 or Tara Jeji at RIM (313) 966-7502. Participants may receive up to $50 plus travel expenses.
We especially encourage women of color to enroll.