Former Patient Plays Point Guard on Paralympics Team USA

"Tell them the kid who started out on the 5th floor of Mott Hospital 10 years ago is going to the Paralympics, and he remembers where he came from!" suggests Paul Schulte, emphasizing his interest in "giving something back" to people with spinal cord injury. He was recalling his days spent in rehabilitation in the University of Michigan Health System following the motor vehicle crash, which resulted in his L-2 injury. He particularly noted how influential Dr. Edward Hurvitz was in his life.

Now 21, and featured prominently in the news, Schulte was recently selected for Team USA, the men's wheelchair basketball team heading for Paralympics 2000 in Sydney, Australia in October. He joins seven others from the 1998 Gold Cup team that won the World Championship. He was selected for the team during a mid-May weekend of tryouts at the University of Michigan Crisler Arena. Now he is spending the summer in the area, and he works out regularly with Ann Arbor players. A native of nearby Manchester, he attends the University of Texas-Arlington on a full basketball scholarship. He is a junior in mechanical engineering.

CNN featured Schulte in a June update on Team USA. Network interviewers tagged the six-foot point guard as the "up-and-comer," looking to take over the leadership of the team in the future. As the only college player, he is the "baby" of the group, chosen from the best players on collegiate and community teams across the country. The oldest at 47 is veteran David Kiley, "in his day, the Michael Jordan of wheelchair basketball," according to Schulte.

Schulte has an international classification of 3.0, in a scale where 1.0 represents a very high-level injury, with limited trunk and back muscles. During a game, players representing no more than 14 total points can appear on the floor at any one time. Schulte is a valuable asset to his team, since he easily matches in ability with opponents, such as amputees, who are rated 4.5.

Schulte will have a busy summer before he returns to school in mid-August and begins daily two-hour practices for the fall-winter collegiate season. He travels to several weekend training camps, climaxing in a world tournament in Warm Springs, Georgia, in August. There, the top eight teams will compete, each seeking to gain the mental edge for the Paralympics. He hopes one more U-M training camp will be scheduled, allowing him to return to Ann Arbor, just before the trip to Australia. He is quick to point out that disabled athletes do not receive very much recognition, and limited sponsorship and lack of sufficient funding means team members sometimes must pay their own travel expenses.

Schulte looks forward to returning to Michigan permanently after his collegiate career.
Despite his hectic schedule, he is "more than willing to come and talk to kids," and he has spoken to school groups and basketball camps. Well aware of the impact of arriving in a chair, he enjoys relating to people of all ages, putting them at ease, and "making them laugh and have a good time without even thinking about it!"

Conference Encourages People with SCI to "Get Out and Try It!"

Participants rated the recent "Wellness with SCI: A Mind, Body, and Spirit Conference," a resounding success. Attendance was up and enthusiasm was high for the annual educational conference, on the sunny May Saturday, when many people with spinal cord injury gathered at the Detroit Medical Center's rehabilitation center in Novi. Family members, personal assistants, and interested health professionals joined them for the all-day event.

This marked the fifth year of joint sponsorship by the Southeast Michigan Spinal Cord Injury System in Detroit and by the Spinal Cord Injury Model System, in partnership with the Ann Arbor Center for Independent Living. Clark Shuler served as master of ceremonies for the day. He is a peer resource consultant for the U-M Model System, and a member of the Advisory Council.

Participants moved among three series of breakout sessions. In one set, a small group talked with a massage instructor, while another discussed spirituality, and another practiced the imagery and meditation of tai chi. "Get out and try it!" was the advice about warm-weather leisure activities, with the reminder that adaptive equipment brings opportunities people may not have considered before.

Some scrimmaged with the Michigan Thunderbirds, men's wheelchair basketball team, while others learned that swimming is good therapy. "Water is like magic!" freeing people with spinal cord injury to relax, reduce tone, gain strength. "You can do a lot in the water, and you don't have to feel left out!"

At the same time, others frankly addressed issues of relationships and dating. "Men may want to get into intimate situations with me, but they don't want to be seen with me in public!" one woman declared. Another person noted the first question on people's minds, when they are attracted to someone they meet for the first time. "I wonder if this person can have sex." Others asked, "How can you be romantic and a care-giver at the same time? Care-givers get tired and resentful!" The group concluded that communication is what keeps people together, both with and without disabilities.

Some participants went into the kitchen to learn "how to have your cookie and eat it, too!" At the same time, a group attending the fitness and weight-training session heard the advice to drink plenty of water and to eat several small meals each day. "It takes a lot of energy to digest your food!" Another group learned more about the role of acupuncture in pain management.
Humorist Dan Wilkins concluded the day's sessions, reminding his audience that professionals deal with disability only six or eight or 10 hours per day. "We are the experts! We need to teach, and learn from, one another!" Although he has tetraplegia, resulting from a motor vehicle crash in 1980, he quipped that his disability is being married to an occupational therapist, who frequently reminds him, "You can do that! I've seen you do it!"

How to Stay Healthy While Growing Older

You are invited to participate in a new program dedicated to healthy activities that are also fun. It is just getting underway and promotes holistic health (well being of mind, body, and spirit) for persons with spinal cord injury. The program offers six workshops, lasting four hours, with one every other week. They focus upon activities that will likely lead to better health and include relaxation, cooking and eating for good health, skin care, bowel and bladder function, and exercise.

Evaluations of all persons enrolling in the program take place three times--before the workshops begin, after they conclude, and then again four months later. Health questionnaires and clinical measures make up these evaluations. Included are resting heart rate, body mass index, cholesterol levels, testing of key muscle strength, and a hand-crank measure of endurance. To see how effective the workshops are, participants will be divided into two groups. One group will attend workshops and the other will not.

Qualified individuals will be between the ages of 18 and 65, with spinal cord injuries at the C-5 level or below, who have lived with these injuries for two years or more. They must be willing to participate for the full seven months of the study, beginning next spring, and be able to travel to University Hospital, where all evaluations and workshops occur. The program provides compensation of $20 for each trip, plus expenses for parking and mileage.

Please call our office, as shown on the address panel, if you are interested in learning more about the program.

RESEARCH HIGHLIGHTS

Sexuality Talk Concludes 1999-2000 SCI Lecture Series

Monthly SCI lectures sponsored by the U-M Model System concluded in May with Dr. Theodore Cole's lecture, playfully entitled, "Sexuality and Spirituality: Taboo or Not Taboo, That Is the Question." Dr. Cole reminded his audience that in social settings we are often advised to avoid talk of politics, religion, and sex. In health-care settings,
however, it is important for clinicians to be able to skillfully explore spirituality and sexuality. This exploration may reveal strengths for affirmation, or it may open up painful, anxious parts of the individual for healing.

Dr. Cole emphasized the need for a sincere and neutral approach to any discussions. While neither client nor clinician may feel comfortable at first, these discussions may empower the client in self-healing, which is necessary in all cases of rehabilitation following severe disability. Recent studies of physical disability and spirituality show that spiritual beliefs are related to feelings about well-being, quality of life and life satisfaction.

Dr. Virginia Nelson, Chief of Rehabilitation Services at C. S. Mott Hospital, delivered the April lecture. She discussed plans that are made to improve quality of life for children and adolescents who require ventilator assistance to breathe, as they are discharged from the hospital. Preparing for discharge involves checking the readiness of the patient, family, equipment, and community.

In February, Rehabilitation Engineer Dr. Simon Levine described direct-brain interface for people with high-level spinal cord injuries.

National Conference Spotlights Staying Healthy with a Disability

"A Wellness Agenda" was the focus of a national conference on disability and health held in Dearborn, Michigan, in early May. The sessions drew leaders in the field of wellness from across the country. They met with consumers with spinal cord injury and other disabilities, staffs of Centers for Independent Living (CILs), and rehabilitation professionals. The Centers for Disease Control and Prevention and the Michigan Association of CILs co-sponsored the conference, and several representatives of the U-M Model Spinal Cord Injury Care System were among presenters and planners.

Participants praised the rich interactions they experienced, both among audience members and between audience and speakers, throughout the two days of the sessions. These opportunities for face-to-face contact are important steps to help "bridge the gap" between consumers and researchers. They bring results of current research directly to the individuals whom are most affected.

Sunny Roller, coordinator of the project's annual spring outpatient conference that is highlighted in this issue, was a panelist. She discussed barriers to health promotion and wellness for women with disabilities. Barriers may be pain and fatigue; cost and transportation; other health conditions besides the person's spinal cord injury; and beliefs about health, such as the feeling, "I'm as healthy as I'll ever be!" In a separate presentation, Ms. Roller emphasized the important roles CILs are just beginning to play in the development of wellness programming.
A pre-conference workshop introduced the program, "Living Well with a Disability," developed in Montana and now being carried out by a few CILs across the country, one of them in Holland, Michigan. Along with centers in Grand Rapids and Lansing, the Holland CIL will serve as a demonstration site, showing how the program is put into operation and also offering training to other centers across the state. This program shows promise in decreasing complications of disability, such as reducing the number of times people need to receive medical attention in an emergency room.

James Magyar, Director of the Ann Arbor CIL, is excited about the curriculum, because the program is consumer- and community-based, rather than depending upon physicians, therapists, and other health-care professionals to put it into effect. He expects to begin to develop it this summer, with his staff members who attended the workshop.

Health and wellness make up a major share of both the inpatient and outpatient sessions of the Hospital to Community Program, which has been pioneered by the U-M Model SCI Care System in partnership with the Ann Arbor CIL. Magyar will work with the coordinators of this program to incorporate "Living Well with a Disability." He is looking for other community partners, as well.

Co-director Dr. Denise Tate presented an evaluation of wellness and health-promotion efforts. She described results of her recently completed research on wellness of women with late effects of polio that can be applied to other disabilities. Her work indicated that health behaviors improved and positive health behaviors increased, following an eight-week program emphasizing nutrition, exercise, and stress management, as described in the Fall 1999 edition of SCI access. The new wellness program that we announce in this issue develops from this work.

Former co-director of the project, Dr. Theodore M. Cole, spoke about the changing face of disability research during the past 40 years. Changes in the way society views disability affect employers, scientists and educators, health practitioners, and policy makers, as well as individuals and their families.

To find out more about wellness programming in your community, you may call the Michigan Disability Rights Coalition, at (800) 760-4600. They can give you information about the CIL closest to your home.

RESOURCE CORNER


Former patient and newsletter reader Jane Zezula-Nagi, who has a spinal cord injury that is classified as non-traumatic, writes: "This book is a helpful reference guide for
wheelchair users and a window on the world of disability for able-bodied people as well. It's an informative, encyclopedia-type book, which reads like a novel, because each page is laced with personal stories and anecdotes. The book methodically led me through the world of disability issues. As a paraplegic for four years, I have tried to become familiar with as many of these issues as possible. The author has conveniently laid them all out, and he makes it easy, not only to learn about the issues themselves, but also to discover what disabled people think.

"The chapter on the experience of disability helped me to clarify my own ideas, by reading how other disabled people feel. This chapter illustrates the reason for misconceptions and misunderstandings between able-bodied and disabled people, by highlighting the fact that many in the general population are unsure about how to confront someone with a disability. "Getting out There" is a chapter describing laws and regulations relating to travel and transportation issues in a concise and organized way. This was especially informative for me, since I have lived and traveled in Asia for the past two years.

"The last section lists numerous organizations, resources, and companies to contact for products and information; many of these include e-mail addresses. Everyone needs this book on the shelf at home or in the office. It's an easy read! Choose the sections that interest and inform and read the rest later!"

Editor's Note: While living and traveling throughout Asia, Ms. Zezula-Nagi has written several articles for an English-language magazine of Shanghai about getting around in a wheelchair. Humorously, she describes accessibility in China, "It's really just a one-liner-there is none!" In a population of 1.2 billion, she says she has seen only three or four disabled people in public in two years. "A fair number of people are in wheelchairs, but they are all elderly!" After living in China and traveling to a number of third-world countries, I'm so thankful that I live in the United States. Of course, there is always work to be done to make public places more accessible and people more aware of accessibility issues, but I can tell you that I am very lucky to be an American!"

Ms. Zezula-Nagi says she has lots and lots of stories to tell about getting around, dealing with cultural/language issues plus accessibility, and she is happy to share these with our readers. A future issue will highlight her experiences. In the meantime, you may contact her with any questions you have about international travel. Call our office for information.