

PROJECT NEWS

PROJECT ENABLE

A new sign hangs in the hallway of the spinal cord injury unit at SCVMC asking onlookers if they've been enabled. "Hmmm, I'm not sure. Does it have something to do with fertility?" questioned one interested party.

Not exactly!

Project Enable is, however, an exciting, new feature on the SCI unit at Santa Clara Valley Medical Center. It offers Internet access to patients with SCI and the rehabilitation staff, for the purpose of discovering SCI resources, educational materials, and peer support. But even more than that, it opens the door to a new environment that is rapidly growing in today's society.

The idea for Project Enable was actually *conceived* many years ago when the Internet was first becoming popular. The patients, peer supporters, and therapy staff all recognized the huge benefit of an Internet connection for the SCI unit. However, two major *barriers* stifled this plan for years...money and somebody to go after it.

TBI and SCI Projects employee **Mark Olson** approached the Valley Foundation for funds to start Project Enable. The application was approved, and we received a check for \$10,000!

Receiving the check, however, did not mean that the job had been completed. Equipment and accessories had to be purchased. A high speed ISDN phone line had to be installed and our county phone guys had to finish the wiring from the basement to the SCI Gym. Then, an Internet service provider was selected and the computer was configured, climaxing in the very first high speed connection at over 230K bps. (33K and 56K bps are

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BRAIN AND SPINAL CORD INJURY GRANTS

INTERACT

Karyl Hall Retires from SCVMC

There are some things you think will last forever. There are people that you see every week and assume that they will always be around. Nothing, however, lasts forever. The TBI & SCI Grants regrettably announce the retirement of **Karyl Hall, Ed.D.**

Dr. Karyl Hall is a Research Psychologist who serves as Research Director for the Rehabilitation Program at Santa Clara Valley Medical Center in San Jose, California. She directs the Traumatic Brain Injury and co-directs the Spinal Cord Injury Model Systems of Care at Valley Medical Center, funded by the National Institute on Disability and Rehabilitation Research. She also is a Clinical Assistant Professor at Stanford University.

Dr. Hall is retiring after more than 20 years' experience in rehabilitation research and outcomes measurement. Her primary interests lie in the cost/benefit of rehabilitation, and functional assessment in rehabilitation. She was instrumental in the development and testing of the Disability Rating Scale (DRS) and the Functional Assessment Measure (FAM), and has over 60 publications to her credit in the field of rehabilitation.

As a Research Psychologist at the University of California, San Francisco, she conducted research on the application of the evoked potential technique in brain and spine trauma. She was Project Co-Director of the Model System of Care for SCI at SCVMC from 1983 through 1985. She then became Director of the Evaluation and Learning Laboratory at the Palo Alto VA Medical Center, studying the use of robots by individuals with high tetraplegia. Of late, Dr. Hall was concentrating on the administrative, research, and dissemination aspects of both the TBI and SCI Model Systems grants. In these capacities she has been a consultant for physicians, nurses, and allied rehabilitation staff on research methodology and statistics, taught research design and methodology, and has supervised the clinical programs and research studies coordinated by the Model Systems grants. She has been involved in development, coordination, and analysis of numerous databases in her career.

Dr. Hall has worked with Santa Clara Valley Medical Center staff for over 17 years. During her tenure as Rehabilitation Research Director, funding for grant related activities has tripled. She has been in demand nationally and internationally to give keynote addresses on outcome measures, assessment scales and cost/benefit analyses. Under Dr. Hall's direction the national Center for Outcome Measurement in Brain Injury (COMBI) was started at SCVMC. Through her skills in grant writing and public presentation she has brought SCVMC's name into the national spotlight. Recently, SCVMC was named by U.S. News and World Report as one of the top 20 rehabilitation centers in the country.

Dr. Hall is retiring in the late fall to her beautiful home in Carmel, where she hopes to spend more time with her husband Fred Nelson, gardening, and renovating the historical landmark on their property, the Door House. The TBI & SCI Grant staff wish her the best and thank her for all she has done for the TBI & SCI Projects, SCVMC, and the rehabilitation community. Good-bye Karyl. We sure will miss you. ■



Karyl Hall, Ed.D.

SAFETY EDUCATION/DISABILITY AWARENESS

Prevention Awareness

Sometimes we don't readily see the results of our efforts in reducing the number of injuries and fatalities. Legislation, and more importantly, enforcement of these laws have made a significant difference. CONSIDER:

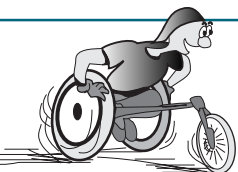
- ✓ This year motorcycle helmet laws will save about 600 lives and prevent over 2,000 injuries while saving more than \$6 billion in highway crash and medical costs.
- ✓ In 1992 alone, California's mandatory motorcycle helmet law may be credited with saving 92 lives (a 37.5% reduction in deaths) and saving \$86 million in lost productivity (University of California, San Francisco). Use rates were above 95% (Journal of the American Medical Assn.).
- ✓ Over the past ten years safety belts have saved 55,000 lives and prevented over 1.25 million injuries and accounted for a total savings of \$88 billion in crash and medical costs from 1984 to 1993.

—*Highway Safety Talking Points*, Advocates for Highway and Auto Safety, Washington, DC; August 1995

- ✓ Children ages 9 and under are at greater risk for bicycle-related head injuries and are the age group least likely to wear a bicycle helmet.
- ✓ Universal use of bike helmets by children ages 4–15 would prevent between 135 and 155 deaths, between 39,000 and 45,000 head injuries yearly.
- ✓ To date, 13 states have enacted some form of bicycle helmet legislation, most of which cover only young riders.
- ✓ Bicycle helmets have been shown to reduce the risk of head injury by as much as 85% and the risk of brain injury by as much as 88%.

—*Fact Sheet: Bicycle Injury*, National SAFE KIDS Campaign, Washington, DC; November, 1995

These FACTS and FIGURES were compiled by the Children's Safety Network. For a complete copy or more information contact: Ann Hammond, MS, MSLS, Injury Data Technical Assistance Center, 6505 Alvarado Road, Suite 208, San Diego, CA 92120, 1-(619) 594-3691. ■



13TH ANNUAL 5K WALK & ROLL-A-THON

Saturday, Oct. 3, 1998, Almaden Lake Park, San Jose
Registration 8 AM Walk•Roll•Run 9–11 AM

Food! Refreshments! Music! Proceeds used to help expand public awareness, education and services for brain injury. T-shirts will be given to participants with donations or pledges totaling \$25 or more (while supplies last). Call Christine Camera at (408) 295-4119 for more info. ■

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standard speeds over regular phone lines). It's really quite exhilarating!

Already, we have seen the rapidly rising impact of Project Enable. One patient was filled with hope when he realized the potential of what he could do with a computer, assistive technology, and the Internet.

It is our desire and passion that Project Enable would ignite hope in all the patients on the spinal cord injury unit.

If you have Internet access, you can 'get enabled' by visiting Project Enable on the World Wide Web at <http://www.best.com/~enable> or send an email to Project Enable at enable@best.com. ■

FEATURED STAFF

Mark Olson: Mark of Greatness

Meet another of our multi-talented staff. He's **Mark Olson**, Spinal Cord Injury Researcher Extraordinaire. At least that's what his business cards say...



Mark Olson

But seriously, Mark is an important member of our Spinal Cord Injury (SCI) Grant staff. He coordinates and collects information for the National Database for SCI. He abstracts all of

the medical information collected while patients are hospitalized, and coordinates the yearly follow-up interviews. Mark is one of the grant staff you might meet on the rehabilitation unit at SCVMC, collecting informed consents to participate in our projects. He also makes one month follow-up calls to check up on our patients after they go home.

Mark is also involved in studies involving parenting after SCI, long term follow-up on aging after spinal cord injury, SCI program evaluation, the impact of minority status and SCI, and a study looking at SCI caused by falls. Whew! When he wasn't busy with these studies, Mark wrote a grant and implemented Project Enable, a project that brings Internet access to individuals in our SCI rehabilitation unit.

So who is this guy? First he's a family man as well as a new Dad! His daughter Rachel is just one month old! His other daughter Hannah is almost two. Few knew (until now) that he serenaded his wife Tina when he proposed.

Mark has his Masters of Public Health from Loma Linda University. His emphases were in international health and maternal child health. He would

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SUPPORT CORNER

TRAUMATIC BRAIN INJURY (TBI) SUPPORT GROUPS

- **Mild Brain Injury (MBI) Group**
For individuals in the community with brain injury, and friends and family. Meets the fourth Tuesday of each month at 7 P.M. at the Cypress Senior Center, 403 So. Cypress Ave., San Jose. Contact **Dan Mayclin, (408) 295-9896, x19.**
- **Very Important Patient (VIP) Group** Includes inpatients, outpatients, individuals in the community with brain injury, and friends and family. Meets the fourth Wednesday of each month at 7 P.M. at Santa Clara Valley Medical Center, Rehabilitation Conference Room. Contact **Dan Mayclin, (408) 295-9896, x19.**

SPINAL CORD INJURY (SCI) SUPPORT GROUPS

- **SCI Support Group**
Includes individuals in the community with SCI, and friends and family. Meets the third Thursday of each month at 7 P.M. at the Cypress Senior Center. Contact **Richard Patterson, (408) 295-9896, x12.**
- **SCI Women's Peer Support Group** Includes women in the community with SCI. Meets on the fourth Thursday of the month from 1:00 P.M. to 3 P.M. in the Third Floor Conference Room, 2400 Moorpark Ave., San Jose. Contact **Janie Whiteford, (408) 295-9896, x42. ■**

Psychosocial History: What Is It, and What Role Does It Play in Rehabilitation?

The Problem

Many therapists know that the "psychosocial" problems following traumatic brain injury (TBI) can be far more disabling and enduring than the physical injuries.

Psychosocial deficits include negative changes in emotions, thinking and social interactions. Research has shown that most recovery of physical and mental functions occurs within six months of injury, being tied in to the healing process in the brain.

Later recovery involves adapting to deficits. This later recovery is thought to be heavily dependent on pre-injury and social factors.

Traumatic brain injuries typically happen to young men, often with a pre-injury history of alcohol/drug abuse, learning disability, or high risk-taking behavior. After the injury and discharge from acute care, these problems can be exaggerated by the brain injury. Personality, behavior, and emotional reactions, including anger, are often involved. Holding a job, if able to work, can become much more difficult. Judgement can be impaired, and alcohol/drugs can be an easy escape from problems.

The Solution

Factors that may lead to future problems, such as ongoing substance use, or behavior

that leads to legal problems or psychiatric hospitalization, should be a concern of payers and the community at large. Judicial investment in resources to minimize these psychosocial risk factors may save health care and law enforcement dollars in the long run, not to mention stress on the individual and family, both for the uninjured and already injured populations.

Some examples for which we already have models include 1) substance abuse programs for individuals with TBI, 2) individual, family, and group therapy for management of common behavioral disturbances (anger and frustration management), 3) peer support, offered both acutely and in the community, and 4) supported volunteer programs for those unable to work competitively.

For support groups and other community resource information, call **Dan Mayclin, Ph.D. (TBI)** or **Debbie Burdsall, OTR, MPH (SCI)** at our ResourceLine: **1 (800) 352-1956 x24.**

You can also check out our online resource directories, either in hard copy or online (<http://www.tbi-sci.org>) for community resources. ■

Study Announcements

Women with SCI Sought for Sexual Response Study

We are seeking 50 women with SCI, at or below the level of T6, particularly incomplete injuries. An honorarium of \$500 plus travel expenses will be paid to those who complete the study. For more information, call **Marie Dziekan, M.A.** at **1-800-248-3221 ext. 2711.**

Community Integration Study

We are also seeking men and women with SCI who are of Asian or American Indian descent to participate in an extensive telephone survey. The survey will help us learn more about the well-being of people with spinal cord injury, including both physical and emotional health. A stipend of \$50 is being offered to participants who complete the interview. If you or someone you know is interested in participating in this study, please don't hesitate to call us at **1-800-352-1956 ext. 17 or 24.**

Parenting by Mothers with Spinal Cord Injury

Are you a mother who has had a spinal cord injury before your child reached the age of two? If this describes you, we need your help! We are looking for participants who will fill out a mailed questionnaire. We are offering an incentive of \$50 for participation in this study. For more information, please call **Mary Lou Gustafson** at **1-800-352-1956 ext. 10. ■**

What It's Like to Be in a TBI Support Group

Everyone needs someone to talk to. Support groups are made up of individuals who get together to talk and listen to one another. The TBI Grant has made peer support an important part of its programs.

There are two Traumatic Brain Injury support groups sponsored by the Traumatic Brain Injury grant: one meets on the 4th Tuesday of each month at the Cypress Senior Center and the other meets on the 4th Wednesday of each month at the Rehab Conference Room at Valley Medical Center. These groups are for individuals with brain injuries, and their family, friends, or caregivers. They are open forums for sharing both problems and solutions.

When someone new joins the group, everyone in the group is very welcoming and helpful, in some part because

they know what the person is going through. They have been through it themselves. People in these two groups know that it is scary to come to your first group. They know that newcomers have the worry that they won't know what to say or that they'll say the wrong thing or that they'll try to say something and nothing will come out or, perhaps worst of all, that they might cry. The people who have been in the group a while have been there and have done that. They bought the T-shirt and wore it out. They know. And they found that they not only survived their first group but felt a whole lot better after they came to the group.

Why would they feel better, you might ask? They feel better because they now know that they're not alone, that others have gone through this experience and not only survived it, but unbelievable as it sounds, **grown** from it. They

feel better because they know that they can learn from others' experience. They even feel better because they know that some day they can help others through this terrible time in their lives.

So, take a chance. Come to one of the groups. Be willing to be scared, worried, mad, or even like some who feel that having a traumatic brain injury is no big thing. We listen to all who come. In the roughly 10 years these groups have been in existence, we've had no fist fights, hurling of objects [or people], no rude gestures, or unkind words. We have had a lot of caring, sharing, laughs and fun times. Try it, you'll like it.

For more information on the TBI Grant's support groups, please call **Dan Mayclin** at 408/295-9896 x19 or email him at danm@tbi-sci.org ■

Mark Olson, from Page 2

like to someday be more involved with overseas mission projects involving community development and church planting.

Mark's interests include playing guitar, mountain biking, golf, fishing, hiking, photography, the Internet, cross-cultural missions, and spending time with his family. Watch out for Mark if he offers to play you any sort of game.

He may look calm and quiet, but inside he's a true competitor.

Those of you participating in the SCI national database, please say "Hi" to Mark when he calls. Make sure you ask him your questions, too. The SCI Grant is always looking to give out information on resources available to individuals with SCI... Thanks Mark, for all you do! ■

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INTERACT

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