

## PROJECT NEWS

### Staff & Other Changes

#### RRC STAFF CHANGES

A couple of Rehabilitation Research Center (RRC) staff changes you may need to know about. Welcome **Gail O'Mara**, a new Research Assistant. Gail will be working on a number of studies including Aging with Spinal Cord Injury (SCI), Mentors and SCI, the SCI National Database (follow-up) and the Impact of Post-traumatic Seizures after Traumatic Brain Injury (TBI). Please be nice to Gail when she calls!

Long time TBI Follow-up Coordinator and Community Liaison, **Mary Lou Kohlmeier**, has left to pursue a new career with clinical trials. **Laura Jamison** will now be following individuals participating in the TBI National Database.

#### NEW LOCATION

Within the next six months the RRC offices will be moving to a new location on the Santa Clara Valley Medical Center campus. Right now the location is a secret, but watch for a mailer with our new contact information.

#### NEW ORGANIZATION

After over 12 wonderful years our affiliation/employment with Professional Group (PG) is coming to an end. PG has been the administrative agency for the RRC handling our accounting, payroll and benefits. But PG is closing its doors as of July 1, 2003. Which means that all of the RRC staff will be starting as new employees of a different organization. Which one? That's also a secret.

#### NEW TBI NATIONAL DATABASE

As part of the new grant cycle, the TBI National Database has been completely overhauled. Two areas may be of interest to ongoing participants:

- 1) the 2-3 hour neuropsychological testing battery has been removed from both the inpatient and follow-up years.
- 2) there will not be structured interviews every year. The new schedule for interviews will be at post TBI years 1, 2, 5, 10, & every 5 years after that. Don't worry, we'll still stay in touch!

# inter@ct

RRC News  
Research Activities  
Community Programs

Rehabilitation Research Center for TBI and SCI

## TBI Grant awarded to SCVMC

### The Northern California Traumatic Brain Injury Model System

Santa Clara Valley Medical Center (SCVMC) has been selected to receive funding from the National Institute on Disability and Rehabilitation Research (NIDRR) as a Traumatic Brain Injury (TBI) Model System. SCVMC is one of only 16 such centers across the U.S. The grant will be in the amount of \$365,000 each year for the next five years. Eighty percent of the total cost of the project is coming from federal funds, with the remaining 20% representing in-kind contributions such as space, physician time and other staff time. Reflecting past achievements, community support for this project was voluminous. Letters of support for the project were received from Anna Eshoo, Zoe Lofgren, Don Perata, John Vasconcellos, Liz Figueroa, Rebecca Cohn, Virginia Strom-Martin, Family Caregiver Alliance, Silicon Valley Independent Living Center, the Brain Injury Association of America, the State of California Department of Rehabilitation, Services for Brain Injury, In-Home Supportive Services Public Authority, Mexican American Community Services Agency, local rehabilitation professionals, and a host of individuals with brain injuries and their families. Thank you for your support!

Individuals with TBI are a major portion of the clientele at SCVMC, a level 1 trauma center. Since 1976, SCVMC has provided categorical care in a Brain Injury program for inpatients and outpatients and was first an RSA, then a NIDRR designated Model System for TBI since the inception of those programs. Over this time period, with the support of the county board of supervisors, NIDRR, and the community, the continuum of care has grown to encompass those with mild TBI, very severe brain injuries, and those transitioning into the community. Specialized programs have been designed to maximize the rehabilitation potential of those with TBI. Referral networks of individuals for inclusion in the Model System have been expanded to San Francisco General and Eden Hospital in Castro Valley.

Based on input from individuals with TBI in our community, this grant's focus is on the "Health and Function" priority suggested by the U.S. Department of Education. Two studies are designed to better characterize the type and impact of fatigue on this population: 1) a cross-sectional study of individuals at least one year post-TBI and 2) a longitudinal study that focuses on the evolution of fatigue over the first two years post-injury. Both studies will utilize standardized measurements of fatigue, as well as those for depression/affective disorders, sleep disturbance, activity scales and measurements of hormone levels reflective of the health of the neuroendocrine system. Two additional studies are planned to characterize the impact of late posttraumatic seizures on recovery: 1) a study utilizing data in the TBI National Database that compares the functional, vocational, and medical complication outcomes of those with and without late posttraumatic seizures; 2) a study in collaboration with Denver Hospital Medical Center that will interview individuals at both sites who participated in a previously funded NIDRR grant on seizure risk identification. This study will further evaluate barriers to the environment, transportation and challenges in control of their seizures.

Another major project of the TBI Model System centers is contribution to a national database. Information is collected that reflects the acute and rehabilitation hospitalization. Follow-up information is also collected on an annual basis after injury, measuring community integration, cognitive functioning, life satisfaction, and medical issues. SCVMC helped

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## NEW TBI GRANT (CONT)

design the original database, now in its 14th year. Over this next cycle, many SCVMC participants will be interviewed as many as 18 years post injury.

Dissemination efforts will build on our already active Center for Outcome Measurements in Brain Injury <[www.tbims.org/combi](http://www.tbims.org/combi)> (COMBI) with cooperation and collaboration from at least 15 other centers. The COMBI project is an important tool for TBI researchers worldwide as it seeks to disseminate important information on over 21 brain injury outcome and assessment scales. Additional dissemination will occur via our main website <[www.tbi-sci.org](http://www.tbi-sci.org)>, local/national/international presentations, newsletters, and peer-reviewed publications.

Grant leadership is provided by Co-Principal Investigators Jeffrey Englander, M.D., Vice-Chair of the Department of Physical Medicine and Rehabilitation, and Tamara Bushnik, Ph.D., Director of Rehabilitation Research. Other strengths of SCVMC include: a stable staff experienced with the Model Systems; an excellent follow up record; proven leadership as chairs of the Medical, Dissemination and Data committees; and an excellent network of services that has always included individuals with disabilities, both in paid and volunteer positions. The staff research capabilities have been dedicated to these efforts with the potential of a promising new partnership with Pharmacia Inc. to help defray some of the laboratory testing costs.

We look forward to our new five year program of research, information dissemination, and community activities. Thanks again to everyone who took time to give input to our proposal or wrote a letter of support.

## STAFF SPOTLIGHT

### Principal Peer Supporter

# Sherri Rogers



Sherri Rogers

Peer support programs don't work without the hard work and dedication of volunteers and support staff. No one knows this better than Sherri Rogers who has been involved with our Traumatic Brain Injury (TBI) Peer Support program since 1995.

Sherri makes sure that our TBI Peer Support Program runs smoothly, coordinating volunteer schedules and taking care of the paperwork the program generates. She prepares monthly calendars for the peer supporters who visit patients at Santa Clara Valley Medical Center (SCVMC) on Tuesday, Thursday, and Sunday evenings. Sherri makes reminder calls to each peer before

their scheduled visits. She also prepares the materials that the peer supporter will need during their visit to make sure that patients and families get needed resource information.

Sherri also helps coordinate the telephone support part of our support program, calling people who would like to talk, but cannot attend our regular support meetings. When you receive a postcard notifying you about our upcoming Mild Brain Injury (MBI) or Very Important Patient (VIP) support groups, you can also thank Sherri. She organizes the mailings.

You can also find Sherri at any number of local community events supporting brain injury, including Brain Matters, the Brain Injury Awareness Games, and even Christmas in the Park (Did you know that the Rehab Research Center has their own tree? Shame on you. Next year you better get to Plaza de Cesar Chavez and see it.)

In her spare time, Sherri has been collecting updated information for the next version of the Traumatic Brain Injury Resource Directory (TBIRD), contacting over three hundred agencies and professionals for updated information. Sherri also makes hospital visits with the other peer supporters. Oh yes, in what little time is left, she's also a Raiders fan.

On the importance of peer support Sherri said, "It's important for patients and families to have someone to talk to. There are usually a lot of questions, and peers have time to talk. The peer supporters know what it was like to have a brain injury and be in the hospital."

Sherri, thanks for all your hard work and drive to make the TBI Peer Support Program (now going into its tenth year!) such a success. For more information about the program, contact Rich Patterson at (408) 295-9896 x12.

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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 second and fourth Tuesday of each month at 7 p.m. at the Cypress Senior Center, 403 So. Cypress Ave., San Jose. Contact **Richard Patterson** at (408) 295-9896, x12.
- **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 6:30 p.m. at Santa Clara Valley Medical Center, 2nd Center Day Room (2nd Floor). Contact **Richard Patterson** at (408) 295-9896, x12.

### 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 Friday of the month from 12:00 p.m. to 2 p.m. Contact **Janie Whiteford**, (408) 295-9896 x42 or at (408) 356-6034, for the location.
- **Family & Caregiver Support Group**  
Includes family, caregivers and friends. Meets every other Thursday at 6:30 p.m. at Santa Clara Valley Medical Center, Rehabilitation Conference Room. Contact **Dan Mayclin** at (408) 860-7883 (pager).

## SPINAL CORD INJURY RESEARCH

### One-on-One Mentoring/Peer Support and SCI

The purpose of the One-on-One Mentoring study is to compare the physical and psychological health of acutely injured individuals with spinal cord injuries (SCI) who participate in one-on-one mentoring to those individuals with acute SCI who do not participate in a mentoring program. It seems pretty obvious that individuals getting more support would do better, but the research is poorly documented. Peer support is a growing area of interest, but lack of rigorous research means that its efficacy is in question. Completing studies like this will hopefully make it easier to get more peer support programs started as the benefits will be clearly documented.

So who are our mentors? Mentors are individuals with SCI who have been injured for at least two years and have been carefully chosen and trained by our Peer Support Coordinator, **Richard Patterson** and Santa Clara Valley Medical Center (SCVMC) Clinical Psychologist, **Penny Hogg**. Mentors spent 8 hours learning about communication, problem solving skills, recognizing suicidal thinking, how to be empathetic, and coping mechanisms used by persons following serious injury. Many of the mentors have been volunteer peer supporters as well.

The primary responsibility of the mentors is to act as role models for the acutely injured individuals. The mentoring relationship will start two weeks before a person is planned to be discharged. The mentors will be contacting their peer once per week by phone and meeting with them at least once per month in person. It is our hope that the mentors will assist their peers with their family, friendships, recreational programs, peer support meetings and outings. Mentors will be paid a stipend for their participation.

We have the resources to match up to 20 pairs of mentors with peers and our goal is to match the pairs accord-

ing to common social and recreational interests they share, level of injury, and personality.

It has been theorized that one-on-one mentoring is extremely beneficial to those with acute SCI. Hypothesized benefits include:

- **Increased ability** to cope: better equipped to face challenges, to communicate effectively and to be advocates for themselves and others in the community
- **Shared experiences** with another person
- **Learning more** about SCI and community resources
- **Increased self-confidence** and acceptance of spinal cord injury
- **Decreased isolation** and improved ability to get along with others

For this study, participants will either be in a one-on-one mentoring relationship or in a control group (which does not have mentors). Participants will be asked to complete assessments at four different time periods: at discharge from rehabilitation and then at 6, 12, & 24 months post injury. Assessments include questions about depression, level of anxiety, coping, and social skills. Instruments include the Brief Symptom Inventory, Katz Adjustment Scale, and the Social Support Scale.

Participants from this study will be individuals with spinal cord injury that are undergoing inpatient rehabilitation at SCVMC.

When completed, the findings will be prepared for professional publication, but will also be made available to study participants, local support groups, website <[www.tbi-sci.org](http://www.tbi-sci.org)>, and this newsletter. For more information about this study, please contact Gail O'Mara at (408) 295-9896 x25.

## Conference Announcements

### **An Interdisciplinary Approach to Neuro Injuries: Brain Injuries**

April 11-12, 2003, San Francisco, California  
Hyatt Regency San Francisco

Sponsored by Contemporary Forums with educational support provided by Santa Clara Valley Medical Center and Craig Hospital (Colorado). Focuses: 16 concurrent sessions examining neurological recovery patterns that assist in evaluating and management, state of the art clinical and neuroimaging techniques, treatment strategies that influence functional outcome, family communication issues and techniques to facilitate family participation, and effective strategies to manage behavioral issues. Additionally there are two preconference sessions: "TBI- The First 72 Hours" and "Spasticity in Persons with TBI". Contact: Contemporary Forums, (800) 377-7703 extension 3, <[www.contemporaryforums.com](http://www.contemporaryforums.com)>.

### **17th Annual California Conference on Childhood Injury Control**

September 22-24, 2003.

Radisson Hotel at Los Angeles Airport  
Los Angeles, California

Sponsored by the Maternal and Child Health Branch of the California Department of Health Services. The conference is designed to update public health and public safety professionals, nurses, physicians and injury prevention advocates on current issues and future directions in injury epidemiology, public policy and injury prevention strategies. Focuses: State and national injury control priorities, new research on child and adolescent injuries, and injury prevention models and lessons learned. Contact: Center for Injury Prevention Policy and Practice, San Diego State University, (619) 594-3691, <[www.cipp.org](http://www.cipp.org)>.

## Stuff From Other Agencies

### **Silicon Valley Independent Living Center is Selling an Adaptive Cookbook**

Silicon Valley Independent Living Center is selling copies of their cookbook "Because You Must Indulge the Passion: A Cookbook with a Different Attitude". The book includes large print recipes, cooking tips for individuals with limited movement, and suggestions of adaptive tools. Call Frances Merrill at (408) 894-9041 for more information or to order your copy. Mention this ad and receive a copy for a special price of \$10.

### **Out of the Woods:**

#### **A Traumatic Brain Injury Scholarship Fund**

Out of the Woods is a non-profit, tax-exempt corporation comprised of health care professionals and community advocates dedicated to raise and provide scholarship funds for people with traumatic brain injuries (TBI). Individuals with TBI often experience profound losses of their previous roles as employee, parent, or significant other. There are often also insurmountable financial losses. And unfortunately, there continues to be limited resources available, especially financial, for individuals who are brain injured. Out of the Woods' mission is to financially assist individuals with brain injuries. 100% of all proceeds go directly to scholarship fund recipients. The funds aid in their continued rehabilitation, making possible opportunities for them to relearn the basics of activities of daily living; return to a functional, productive life; return to work; modify their home to accommodate their physical limitations; supplement disability income; provide attendant care or respite to the family caring for an individual with a brain injury. The organization is requesting that tax deductible donations be sent to: Out of the Woods, Traumatic Brain Injury Survivor Scholarship Fund, 4592 Fallstone Court, San Jose, CA 95124. For more information, contact Out of the Woods' Director Teri Zimmerman, OTR, at (408) 885-5604 or email [terizimm@earthlink.net](mailto:terizimm@earthlink.net)

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