

# PROJECT NEWS

## Staff Changes

### RRC CHANGES

A couple of Rehabilitation Research Center (RRC) staff changes you may need to know about. Welcome **Naomi McCarroll**, our new Office Coordinator. She's the one you'll talk to on our phone system if you're not sure who you are calling for. Naomi is replacing **Ann Buschmann** (note new married name!). Ann is leaving her old position to collect information for our collaborative "Aging with Spinal Cord Injury" or Longitudinal SCI study. This study is a continuation of a long term project with Craig Hospital in Colorado. Ann will be following individuals who are 15-30 years post their spinal cord injuries. Please be nice to Ann when she calls!

### DEPT. OF PM&R CHANGES

**Drs. Suzanne Groah and Andrea Townson** have both left SCVMC (both with new babies!) They are moving to be closer to their families. Good luck new Moms! (they thought medical school was hard...)

**Dr. Peter Werner** is retiring after 20 years of practice at SCVMC as Associate Chief. Dr. Werner was Principal Investigator of our SCI Model System Project from 1995-2000. We'll miss his expertise and wit. Thanks for all you've done to help individuals with spinal cord injuries.

New physiatrists for SCVMC include **Trinh Tranh, MD; Agnes Wallbom, MD; and David Rosania, MD.** Dr. Tran comes from the Medical College of Virginia/Virginia Commonwealth University. She's joining us as part of our SCI inpatient team. Dr. Wallbom comes from the University of Michigan Medical school. She will be the Director of our SCI inpatient services. Dr. Rosania graduates from the Stanford PM&R Residency program this summer. He will also be part of the SCI inpatient team.

# inter@ct

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Rehabilitation Research Center for TBI and SCI

## TBI Model System at SCVMC

### Five Year Recap and Request

Many of you are aware of the TBI Model System Project at Santa Clara Valley Medical Center (SCVMC). This project, funded by the National Institute on Disability and Rehabilitation Research, will end this October. Staff of the Rehabilitation Research Center (RRC) at SCVMC will be working on a new proposal for the next five year's worth of funding. We thought that this would be a good time to share with you some of the activities/products of this project and ask for your input.

#### Community Activities

Our peer support program allows newly injured individuals and their families to talk with volunteers that have had similar injuries. This connection can continue as the person leaves the hospital for home, providing an important link to resources and support. In the community we facilitate several monthly meetings that allow people to come together, share stories and feelings, and discuss common issues.

The RRC coordinates a quarterly community education series called Brain Matters that provides information to survivors, families, caregivers, and professionals. A variety of speakers present on issues related to brain injury. The events are free and well attended.

We offer free resource information to anyone that contacts our office (by email ([resources@tbi-sci.org](mailto:resources@tbi-sci.org)) or by our toll free phone number, 800-352-1956 x13). We have literally answered thousands of questions with topics ranging from attendant care issues to vocational re-entry. Local resource information was compiled into the *Traumatic Brain Injury Resource Directory (TBIRD)*. We also put out a number of newsletters, *Inter@ct*, describing the activities of the RRC, *Talking Heads*, a local community-based newsletter focusing on brain injury, and *Outcome Oriented*, focusing on outcome measures and assessments.

#### Internet Resources

Our Internet resources are usually used by over 2,000 individuals every week. Over 10,000 copies of the TBIRD have been electronically distributed. Check them out yourself <[www.tbi-sci.org](http://www.tbi-sci.org)>, <[www.tbimatters.org](http://www.tbimatters.org)>, & <[www.tbims.org/combi](http://www.tbims.org/combi)>.

#### Research Activities

We spend a lot of time collecting information on people with TBI who have come to our hospital for their rehabilitation care. The information includes how he/she was doing before the injury, how severe the injury was, how rehabilitation went, and, for every year afterwards, we collect information about how the person is doing back in the community. All of this information is put together with similar information from the other Model Systems in the hopes that we can learn more about TBI. For example, we are looking at whether having a TBI caused by a violent act causes any unusual problems compared with people who were injured in a traffic accident or sporting accident. We are also looking into the predictive value of CT scans, and the impact of pre-brain injury psychosocial history.

#### What Can You Do?

You have a stake in the kind of work that we do, so we would like your feedback on our current projects as well as your ideas about what is important to you. Call us at (800) 352-1956 extension 10 for a confidential survey, or fill one out online at <[www.tbi-sci.org/survey](http://www.tbi-sci.org/survey)>. Thanks for your input!

# UPDATE

## “New” California TBI State Grant Action Plan

In July 1996, the Congress passed Public Law 104-166 (the Traumatic Brain Injury Act of 1996). This Act authorized the Health Resources and Services Administration (HRSA) through the Maternal and Child Health Bureau (MCHB) to award grants to states for the purpose of planning and implementing needed changes in services for individuals with TBI and their families.

In 1999, the California Department of Mental Health was awarded a Planning Grant for the purpose of developing a strategic action plan that would lead to a coordinated system of care for persons living with TBI. The core components of this grant are to:

1. Increase collaboration among California agencies
2. Conduct a needs and resource assessment
3. Develop an Advisory Board
4. Create a statewide action plan

The California TBI Advisory Board consists of 18 members, including one TBI mentor. Numerous surveys from state departments, providers, and TBI survivors/family members have been gathered and analyzed, as well as information from nine public forums and multiple focus groups, to finalize an Action Plan due this summer. It is California’s intention to apply for a 3-year Implementation Grant next December to begin acting on the Action Plan.

Current plans are to unveil the California TBI Action Plan at an event in the Sterling Hotel in Sacramento on August 8th, 2002 from 10:00 a.m. – 2:30 p.m. There will be no charge for attending and lunch will be provided. For further information, contact your Advisory Board Regional Representative, Mary Lou Kohlmeier, at (800) 352-1956 x 13.

## STAFF SPOTLIGHT

### Información sobre Lesión Cerebral por Trauma

## Laura Jamison



Laura Jamison

Meet our talented Data Collector and Spanish Liaison, **Laura Jamison**. Laura has been with the Rehabilitation Research Center since 1994.

Laura collects the information on what happens to individuals after they are hospitalized for a traumatic brain injury. She interviews the patients and families, questions the physicians and treating therapists, and does a lot of poring over medical charts. In all, fourteen pages of information describing medical complications, operations, pre-injury status, functional status, and neuropsychological functioning, are collected for each study patient. Laura is also responsible for

explaining the database study to patients and families and obtaining their consent to collect information and contact them again after they leave the hospital. Laura also completes follow-up assessments on Spanish-speaking individuals on an annual basis after injury. This information is contributed to a National TBI Database in New Jersey.

On the importance of her data collection Laura said, “The information collected here serves a higher purpose. Our data becomes part of a national project, allowing us to learn more about brain injuries. Studies published from this data help not only our new and past patients and families in San Jose, but they also help patients and families throughout the country (and the world)”.

Laura also acts as the RRC’s Spanish Liaison, communicating with our clients and consumers who speak Spanish. She provides information and referral services to individuals who are facing having a TBI and working through a system that is based on English. “Many individuals are not familiar with our health system, and there is a frustration at not being able to access needed services. In an ideal world there would be resources available for human beings, not just select-insured individuals.” Through Laura’s help, many of these individuals and families can access needed services.

When she isn’t working with the RRC, Laura spends every second with her three children (Matthew, Roseanna, & Christopher). Leftover time goes to the family’s three kitties and her husband.

Laura’s quiet efficiency, inner strength, and dedication to individuals with TBI is an important part of our TBI Model System.

*Gracias por hacer una diferencia!*

Thank you for making a difference!

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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 7 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, 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 RESOURCES

### Sexuality and Fertility

Sexuality and fertility are two of the hottest topics related to SCI. Unfortunately, they are also two issues that are often not discussed at length in the rehab setting, for a variety of reasons. Some health care professionals are not comfortable discussing sex and others may not be well versed in the latest and greatest treatments and therapies available. Sexuality is an important topic that merits open and honest dialogue, as the physical limitations imposed by a spinal cord injury do not preclude the physical and emotional need for intimacy and sexual expression.

In recent years more attention has been focused on fertility issues faced by individuals with spinal cord injuries. Over the past decade specialty clinics have been started that deal specifically with the fertility issues faced by men with SCI. A listing of these clinics is available in the SCI Resource Center at the RRC by calling 800/352-1956 x24. Below we have listed some valuable resources and places to go for more information on sexuality and fertility as it relates to SCI.

#### The American Society for Reproductive Medicine

205/978-5000  
FAX: 205/978-5005  
1209 Montgomery Highway  
Birmingham, AL 35216-2809  
E-mail: [asrm@asrm.org](mailto:asrm@asrm.org)  
Website: <[www.asrm.org](http://www.asrm.org)>

#### California North Bay Fertility Association

707/575-5831  
1111 Sonoma Ave, Suite 214  
Santa Rosa, CA 95405

#### The Miami Project Male Fertility Program

University of Miami School of  
Medicine  
305/243-7108  
FAX: 305/243-6017  
E-mail:  
[mfp@miamiproject.med.miami.edu](mailto:mfp@miamiproject.med.miami.edu)  
Website: <[www.scifertility.com](http://www.scifertility.com)>

### BOOKS

*A Guide and Resource Directory to Male Fertility Following Spinal Cord Injury/Dysfunction (2000)*

Maria J. Amador, BSN, CRRN,  
Charles M. Lynne, MD, Nancy L.  
Brackett, PhD, HCLD  
Miami Project to Cure Paralysis  
305/243-7108

E-mail:  
[mfp@miamiproject.med.miami.edu](mailto:mfp@miamiproject.med.miami.edu)

*Finding Love and Intimacy (1994)*

Robert Mauro  
Accent Special Publications  
800/787-8444

*Let Me Count the Ways: Discovering  
Great Sex Without Intercourse (1998)*

Marty Klein and Riki Robbins  
Penguin Putnam Books  
800/526-0275

E-mail:  
[customer@penguinputnam.com](mailto:customer@penguinputnam.com)

*Sexuality After Spinal Cord Injury:  
Answers to Your Questions (1997)*

Stanley H. Ducharme and Kathleen  
M. Gill  
Paul H. Brookes Publishing Co.  
800/638-3775

E-mail: [custserv@phbrookes.com](mailto:custserv@phbrookes.com)

### VIDEOTAPES

*Sexuality Reborn (1993)*

Kessler Institute for Rehabilitation  
800/435-8866  
FAX: 973/243-6869  
1199 Pleasant Valley Way  
West Orange, NJ 07052

### WEBSITES:

**Sexual Health Network**  
<[www.sexualhealth.com](http://www.sexualhealth.com)>

**DRM WebWatcher's Sexuality Page**  
<[www.disabilityresources.org/sex.html](http://www.disabilityresources.org/sex.html)>

**Sexuality and Spinal Cord Injury  
Bibliography**

Medical College of Virginia  
<[www.mcv.edu/spinal/bibliography.html](http://www.mcv.edu/spinal/bibliography.html)>

## Conference Announcements

### Bridges to Employment: Exploring Options for Latinos with Disabilities

August 21-24, 2002, Anaheim, California  
Sponsored by Proyecto Visión/Project Vision, the U.S. National Technical Assistance Center for Latinos with Disabilities based at the World Institute on Disability. Featuring three days of conference sessions, classes, Internet training and presentations in English and Spanish by organizations, employment experts and government agencies offering: job training, job listings, resume assistance, connections, networking, internships, job banks, scholarships, national volunteer service programs, support for higher education, individual development accounts, and advice on a range of strategies from how to look for a job to preparing for an interview to transitioning from benefits to employment. For program information, contact Kathy Martinez, phone 510 251 4326 or email [Kathy@wid.org](mailto:Kathy@wid.org); for registration and logistics, contact Daniel Gutierrez, phone 510 251 4327 or email [Daniel@wid.org](mailto:Daniel@wid.org). More details are posted at [www.proyectovision.net](http://www.proyectovision.net).

### Nonfatal Gun Injuries: The Untold Story

October 27-29, 2002, Chicago, Illinois  
Presented by HELP (Handgun Epidemic Lowering Program) Network and cosponsored by the Rehabilitation Institute of Chicago and Schwab Rehabilitation Hospital. The conference will focus on the personal and societal costs of treatment and rehabilitation as well as strategies for injury prevention. For more information on the conference, contact Chris Young at 773 880-8120.

The HELP Network is the oldest and largest international network of medical and allied professional organizations and individuals committed to reducing the number of deaths and disabilities caused by guns. HELP's website is <[www.helpnetwork.org](http://www.helpnetwork.org)>

## Call for Research Participants

The Palo Alto VA Health Care System is recruiting for two spinal cord injury-related studies. They are looking for people who are interested in participating in research about Heart Rate Variability and ECG (also known as EKG) after spinal cord injury and paralysis. They are also investigating the validity of telemedicine to evaluate three conditions common to patients with SCI.

### HEART RATE VARIABILITY AND ECG STUDY

**Who is Eligible:** Men and women over 18 years of age with a spinal cord injury and paralysis.

**Study Duration:** 2 & 1/2 hour appointment plus 24 hour monitoring (done while you participate in your normal activities).

**Compensation:** \$50-\$100 dependent on level of participation.

**Interested:** For more information on this study, please contact Gail O'Mara at (650)493-5000 x64895 or Amy Hayes at (650) 493-5000 x60179.

### TELEMEDICINE STUDY

**Who is Eligible:** People with SCI/D who: experience spasticity; have a current pressure sore; perform modified independent transfers (*You can qualify with one or more of these conditions*).

**Study Duration:** At most 2 hours for each condition.

**Compensation:** \$25 per condition assessed; up to \$75 per person, dependent on level of participation.

**Study Purpose:** To determine how telemedicine can be used to best care for people with SCI/D, especially those who have difficulty travelling to a SCI clinic.

**Interested:** For more information on this study, please contact Elisa Yao at (650) 493-5000 x63880.

### NOTE:

These studies are not activities of the RRC or SCVMC.

inter@ct

Santa Clara Valley Medical Center  
Rehabilitation Research Center for TBI and SCI  
Medical Staff Corporation  
950 South Bascom Avenue, #2011  
San Jose, CA 95128

[interact@tbi-sci.org](mailto:interact@tbi-sci.org)  
[www.tbi-sci.org](http://www.tbi-sci.org)

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