

PROJECT NEWS

Future Opening of a Women with Disabilities Health Care Clinic at SCVMC

The Outpatient Rehabilitation Clinic has received a two-year grant from The Health Trust (Campbell, CA) to help set up a Women with Disabilities Health Care Clinic. The clinic will be available to all women with disabilities in the county of Santa Clara. The potential health benefits to women with disabilities will include providing preventive health care by a staff knowledgeable about women's health care and disability-specific issues and providing information and education that will improve the chances of the client recognizing a potential health problem and seeking treatment.

The funding will provide partial salary support for a nurse practitioner and a medical assistant who will be available during clinic hours to provide care and education to the clients as well as answer phone calls outside of regularly scheduled clinic hours. The grant will also provide funding to purchase an additional "universally accessible" examination table which can be lowered to a height of 19 inches to make transferring easier and has been adapted specifically for the needs of women with disabilities during physical examinations. The clinic will also offer educational materials that may be viewed while at the clinic. Informational brochures, on major topics, will be developed which may be taken home or given to other health care providers.

The planned opening of the Women with Disabilities Health Care Clinic is July 1, 2000. Please call the SCVMC Outpatient Clinic at 1-800-314-4611 for more information.

REHABILITATION RESEARCH CENTER FOR TBI and SCI INTERACT

What is "Brain Matters"?

By Mary Lou Gustafson

Each year in America, over two million people sustain a traumatic brain injury (TBI), with approximately 75,000 of them exhibiting permanent deficits as a result of their brain injury. Whether the injury is mild or severe, the life of the person with the brain injury as well as the lives of those close to the person are changed forever. As hospital stays are shorter and some people with brain injuries, especially mild brain injuries, are not hospitalized, receiving information and education about brain injury is limited.

"Brain Matters" is a series of community educational events, held approximately every three months, designed to inform and educate the entire TBI community. This includes rehabilitation professionals, TBI survivors, caregivers, and families. The mission is to promote community awareness of the psychosocial and medical complications associated with brain injury, to provide resources to assist in the rehabilitation and community integration of the affected individual, and to provide support for family members and caregivers. The events are also a wonderful way for those with brain injury, their loved ones, and professionals to socialize in a warm, comfortable setting.

On February 10, 1999, "Brain Matters" was successfully launched by the presence of **Claudia Osborn**, a noted author, physician, and individual who suffered a traumatic brain injury. Dr. Osborn presented a fascinating lecture on what it was like to have a brain injury, her rehabilitation process, and the successful rebuilding of herself. Following this, on October 13, 1999, **Harriet Zeiner**, a well-known neuropsychologist in the San Francisco area, discussed relationship issues following a traumatic brain injury. Both events were attended by well over 100 people and favorable feedback was received. Based on the evaluations that were collected, the next event, held March 15, 2000, was entitled "How to Cope with Brain Injury." A group of counselors, psychologists, and TBI survivors were on hand to discuss dealing with memory loss, depression, anger, and problems with organization. Here are some comments from the more than 140 people who attended this most recent event:

"Appreciate hearing from experts who can talk in layman's language."

"Please come again and share what is new in the TBI world."

"This is all great stuff. Thanks."

Del Mar High School in San Jose has been very gracious in providing space for these events. We appreciate the support we have received from the Events Director as well as the groundskeepers in facilitating this event. This accessible facility with ample parking is located at 1224 Del Mar Ave., San Jose, CA. Admission is free, but we request reservations be made at 1-(800) 352-1956 x 20, so we can plan refreshments and seating. The Rehabilitation Research Center for TBI and SCI acknowledges the wonderful support we have received from the **Law Office of Shea & Shea, Valley Medical Foundation**, and part of the proceeds from the **5K Brain Injury Support Walk & Roll-a-thon**.

The next "Brain Matters" event will take place in June. If you would like more information about the program or would like to be placed on a mailing list for upcoming events please call **Mary Lou Gustafson** at (408) 295-9896 ext 13 or email us at brainmatters@tbi-sci.org

FEATURED STAFF

Oz: A Dogged Assistant

Hi! My name is OZ. I may look like a garden-variety golden retriever, but I'm a very special dog. I work as a service dog for my best friend, **Rich Patterson**.

Not every dog can be a service dog, you know. It requires rigorous training, and only a select few will make it. I got my degree at Santa Rosa Canine Companion Service Dog Training School.

I usually let Rich do all the talking, but we thought I'd give you a taste of one of my usual days. At 7am the alarm goes off and my day is under way. Rich lets me outside to do a quick security check. I usually have to erase the suspicious scents from the night before. Rich usually gives me the "better go now" command. Shortly before 10am it's time to dress for work. I am fashionably attired in a wonderful blue cape that fits loosely over my back and signifies that I am working. By remaining close to the front door with leash in mouth I am assured I will not be forgotten. At the opening of the front door I am ready to hop in the van for the drive to work.

Rich is in many ways self-sufficient, but occasionally keys or papers will be dropped. At the command "get it," my many weeks of training kick in. I immediately jump to attention and whisk the items off the floor and place them back into his hands. While at work I am on call. We share an office with very nice folks who are always ready to help Rich when I need a bowl of water. I am always nearby, and early in the day there is a call... Rich has dropped his pen under the desk. When he points to the object to be retrieved, I accomplish it in one swoop and place it in his lap with little lost time or him having to interrupt a co-worker. My reward from Rich is his gentle pats on the head and verbally telling me how much he appreciates me.

Frequently we go to the hospital where Rich will speak with patients with recent spinal cord injuries. This is also an opportunity for me to take their minds off their injury if only for a moment. Sometimes I jump on the patient's bed and give love, or Rich will tell them why I am so important in his life. He explains how I open doors, turn on and off lights, do over-the-counter transactions with his credit card, retrieve objects off the floor, and how I constantly steal the hearts of those he meets. During group discussions I will sit in and listen to Rich while he explains that life continues while facing the challenge of a traumatic injury.

Finally, the work day is over and it's time to go home. At home, Rich takes off my uniform and releases me to scratch, roll in the grass, or get a ball and play catch. My training has taught me that my day is never really over, as my most important duty is to ensure that Rich is always taken care of. I know he loves

me, and that is why it is not hard to return his love, and make life more comfortable and complete.

For more information about Oz, call Rich Patterson at (408) 295-9896 ext. 12. For more information about Canine Companions call (707) 528-0830.



Rich Patterson with his Service Dog, Oz

ANNOUNCEMENTS

NAME CHANGE

No, the name of *InterACT* is staying the same, but the name of the group that writes it isn't. The TBI & SCI Grants (or Projects) is changing its name to the **Rehabilitation Research Center for TBI & SCI**. There was too much confusion about our original name. When we said "Grants" someone always assumed we were giving away money; when we used "TBI Project," we would get confused with the State Demonstration Grants. The new name, we think, is more descriptive.

EMPLOYMENT OPPORTUNITIES

Santa Clara Valley Medical Center's (SCVMC) Therapy Services Department currently has openings for Per Diem and Extra Help Speech and Language Pathologists. Call **Karen Yoshioka** at (408) 885-4453 for more information.

The Department of Physical Medicine and Rehabilitation at SCVMC is looking for a BC/BE physician who is interested in a primarily inpatient position in TBI and SCI inpatient consultation. Research, EMGs and nerve blocks are optional. Extensive resident teaching opportunities. For more information please contact **Michael Berly, MD** or **Jeffrey Englander, MD** at (408) 885-2000.

SBI WOULD LIKE TO THANK...

Services for Brain Injury (SBI) is a community based nonprofit that provides rehabilitation services to people with brain injuries. The agency also supports families and caregivers. SBI would like to recognize the following agencies for grants that help people with their rehabilitation: the **Rotary Club of San Jose** (\$4,742 in visual aid equipment); the **Junior League of San Jose** (\$5,000 in equipment and materials for speech evaluations and therapy); **Smythe European's Empowerment Drive** (\$10,000 to address issues of self care, safety, nutrition, hygiene, and home maintenance after brain injury); and the **Sobrato Foundation** (\$5,000 for speech services).

STUDY ANNOUNCEMENT

Frank Swanson from United States International University is looking for individuals with spinal cord injury who would be willing to participate in a study to help determine the major causes of depression following an injury. You must be at least 18 years of age. For more information visit his website at www.spinalpsyc.org or call (818) 376-1077.

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 the TBI Peer Support Coordinator at (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 the TBI Peer Support Coordinator at (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 the fourth Friday of the month from 12 P.M. to 2 P.M. Contact **Janie Whiteford**, (408) 295-9896, x42, for the location.

TBI ResourceLine:
1-(800)-352-1956,
ext. 13

SCI ResourceLine:
1-(800)-352-1956,
ext. 24

Let's Talk

Rrrring...Rrrring...Rrrring...

Hey, I think that's your phone, and it just might be the Rehabilitation Research Center for TBI and SCI at Santa Clara Valley Medical Center (SCVMC). We call a lot of people to try to learn more about brain and spinal cord injuries.

During rehabilitation at SCVMC, we ask our patients for their permission to collect information from them. In addition to the medical information we collect from the hospital, we also contact them annually to ask questions about how they are doing. Because many of our patients live all over California, we typically collect this information over the phone. Similar information is gathered at 16 other TBI rehab hospitals, and 17 SCI rehab hospitals across America, in an effort to learn more about the issues experienced by persons with brain and spinal cord injuries and their families.

Q- Wow, that's a lot of data, man! Where's the big computer that stores and analyzes all that information? *A- We're glad you asked. The TBI data is managed at Kessler Medical Rehabilitation Research and Education Corporation in West Orange, New Jersey, and the SCI data is managed at the University of Alabama at Birmingham.*

Q- Is this for real? *A- You betcha'! In fact, the SCI National Database has been around for over 25 years and is one of the oldest databases of its kind. As of September 30, 1999, it contained 122,274 forms. Now there's something to write home about.*

Q- Why do they keep calling me? Aren't 25 years of data enough? *A- As we continue to collect information and analyze it, we also continue to learn more about these injuries so that we can constantly improve the rehabilitation process.*

Q- Who picks the questions? *A- Over time, new questions evolve. Many centers are now involved in measuring the impact of managed care and decreasing lengths of stay. The National Institute on Disability and Rehabilitation Research offers grants to exceptional rehab facilities. Each facility is represented with researchers, clinicians, and consumers.*

Q- Why is it important that I participate? *A- Your participation is crucial because each injury is different. The things we learn from your record will help us gain a better understanding of TBI and SCI, a benefit to yourself and others with TBI and SCI.*

Bonus!

Collecting data is not the only reason we call, and certainly not the most important reason. First, we really care about how our participants are doing, not just the numbers and statistics. Second, we want to know how we can be of assistance. Our office is chock full of information and resources to give out freely. We also provide information and resource referral online at www.tbi-sci.org.

Most importantly, we do not want our call to be a burden. Our desire is to continue the relationships we have built with our patients over the years. We'd like to quickly gather the data that is necessary, and then offer valuable resources and information. If you're lucky enough to be part of the database, then we're looking forward to talking to you again soon!



Mark Olson, Debbie Burdsall, Mary Lou Gustafson, or Laura Jamison could be calling you!

STUDY SYNOPSIS

Outcome of Individuals with Traumatic Brain Injury with Different Dispositions from Acute Care

This study was designed to address one of the National Institute on Disability and Rehabilitation Research's research priorities for individuals with traumatic brain injury (TBI). SCVMC is the lead center for this study which will compare the outcomes of individuals who receive inpatient rehabilitation at a TBI Model System hospital to those who receive another kind of treatment/disposition. Alternative dispositions include outpatient rehabilitation, day treatment, skilled nursing facilities, and no treatment (*i.e.*, being discharged to home). The specific hypotheses are that patients admitted for inpatient rehabilitation will have better long-term outcomes at one year and report higher levels of life satisfaction.

An essential component to this study is that the groups are similar on those factors that are known to have an effect on outcomes following TBI. These factors include: demographics such as age and level of education; psychosocial characteristics such as history of alcohol and drug use; and severity of injury factors such as Glasgow Coma Score. In a preliminary study we found that, as might be expected, individuals who are less severely injured tend not to be admitted for inpatient

rehabilitation. However, if people were chosen who had a Disability Rating Scale score of 5 or greater (the lower the score, the better off the person is), the two groups were fairly similar on all other factors.

Therefore, the full study will include only those individuals who had a DRS score of 5 or greater. The two groups will also be selected to be similar on basic demographics as well as severity of injury characteristics. The comparisons will include the following outcome measures, assessed at 6 and 12 months post-injury: Functional Independence Measure; Disability Rating Scale; Neurobehavioral Functioning Inventory; Satisfaction with Life Scale; and Community Integration Questionnaire.

Look for the results to be reported in the *InterACT* newsletter of Fall 2001.

This study is a collaborative effort between Santa Clara Valley Medical Center (lead center), Medical College of Virginia in Richmond, VA, and the Rehabilitation Institute of Michigan in Detroit, MI. This study is supported by the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, Department of Education.

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Please recycle this newsletter: pass it on to a friend.

Phone Extensions

The main number for the Rehabilitation Research Center for TBI & SCI is (408) 295-9896, x10.

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INTERACT

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