

PROJECT NEWS

STAFF CHANGES

Since the last *InterACT* issue there have been a lot of big changes both at the TBI and SCI Grants as well as at Santa Clara Valley Medical Center. Here's a run-down in case you've missed anything. Its hard to follow the game without knowing who the players are.

Long time Follow-up Coordinator and Community Liaison **Pat O'Hare** has retired. Odds are if you ever participated in any of our brain injury studies you probably talked at length to Pat. She also coordinated many of our community activities and programs; especially noteworthy was the Disability Awareness/Injury Prevention Program whose message reached over 100,000 young people! We'll miss you Pat! **Mary Lou Gustafson** (see article in this issue) has taken over Pat's research responsibilities in her new role as Research Associate.

Starting as our new TBI Peer Support Coordinator is **Robin Morgan** who is replacing **Dan Mayclin, Ph.D.** Dan will still be helping to facilitate some of the community support groups.

We also welcome **Valarie Viramontes**, our new Office Manager. Its already clear that Valarie will keep us running smoothly and keep our staff in line.

Over at the rehabilitation hospital, inpatient Spinal Cord Injury physiatrist **Maureen Miner, M.D.** has left to pursue other employment. Replacing her is **Suzanne Groah, M.D.**, recently from Craig Hospital in Colorado where she completed a research fellowship in Aging with Spinal Cord Injury. Dr. Groah is board certified in Physical Medicine and Rehabilitation and will be treating our inpatients with spinal cord injury. Her research interests include bladder cancer in SCI, shoulder pain in SCI, and outcomes after SCI. Welcome Dr. Groah!

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BRAIN AND SPINAL CORD INJURY GRANTS

INTERACT

It's Only Walk & Roll But I Like It...

5K Brain Injury Support Walk & Roll-a-thon

Come join us on October 2nd at Lake Almaden Park for the 5k Brain Injury Support Walk & Roll-a-thon. Volunteers from the Traumatic Brain Injury Project at Santa Clara Valley Medical Center and local agencies, including the Head Injury Recreation Leisure Network (HIRLN), Talking Heads, Services for Brain Injury (SBI) and the Brain Injury Association of California (BIAC), are working hard to provide a day of fun! Proceeds from the event will be used to help expand public awareness, education and local services for brain injury. T-shirts will be given to participants with donations or pledges totaling \$25 or more. Food and refreshments are provided. A pancake breakfast will be served up by Fireman's Local 1165. After you eat up, your 5K constitutional commences. Musical motivation will be provided by Big Fun. For more info on how you can get involved call Services for Brain Injury at (408) 295-4119.

Who are these agencies and why are they fundraising?

The TBI Project at SCVMC

The TBI Project is a research and community service organization located at Santa Clara Valley Medical Center. The TBI Project has a strong Peer Support Program and conducts research looking at ways to improve outcomes after brain injury. Funds from the Walk-a-thon will help fund a community education series which recently brought **Dr. Claudia Osborn** to San Jose for a free lecture. For more info on the educational series, see the article on Brain Matters in this issue or call **Mary Lou Gustafson** at (408) 295-9896 ext.13.

Services for Brain Injury (SBI)

SBI is a community based nonprofit that provides rehabilitation services to people with brain injuries. The agency also supports families and caregivers. Accredited classes in speech and Adaptive PE are available as well as vocational evaluations and trainings. Funds from the Walk-a-thon will provide scholarships for people who are unable to afford even modest tuition. Contact **Christine Camara** for more information (408)-291-2552.

Head Injury Recreation Leisure Network (HIRLN)

The goal of HIRLN is to develop support services and programs and to provide resources for people that have had head injuries. HIRLN focuses on leisure development and socialization skills with activities like barbecues, holiday dinners, camping trips, community events, and whatever else the participants are interested in. Money from the Walk-a-thon will help keep the cost of HIRLN events low and allow us to provide more services in the community. Contact **Tracey MacArthur** for more information (408) 267-0200.

Talking Heads

Talking Heads is a quarterly newsletter providing local information about traumatic brain injury services and programs to survivors and their families. The newsletter is free to the com-

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TBI in Childhood

More than one million children receive brain injuries each year. More than 30,000 of these children have lifelong disabilities as a result of the brain injury. Our nation's special education law, the Individuals with Disabilities Education Act (IDEA), defines traumatic brain injury (TBI) as "an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance..... The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma." 34 *Code of Federal Regulations* §300.7 (12). Children with TBI may have one or more difficulty, including physical disabilities, difficulties with thinking, and behavioral, emotional, or social problems. Early diagnosis and ongoing help can make a big difference in how the child recovers. For more information and publications, check out the National Information Center for Children and Youth with Disabilities website at <http://www.nichcy.org> or call toll free 1-800-695-0285 (V/TTY). Se provee información en Español. ■

Walk & ROLL-A-THON from Page 1

munity and is currently distributed to over 775 survivors, professionals and family members in the Bay Area. Funds from the Walk-a-thon will help defray production and dissemination costs. Contact **Gerard Manuel** for more information, (408) 267-0200.

Brain Injury Association of California

Proceeds from the Walk & Roll-a-thon will go towards BIAC's mission of creating a better future for California Residents with acquired brain impairments. BIAC is a nonprofit agency that is completely supported by individuals and donations. A specific target project is an end-of-year session jointly sponsored by the Dept. of Mental Health and BIAC to evaluate statewide needs stemming from traumatic brain injury. Contact **Barbara Vick** at (916) 442-1710.

Remember:

5K Brain Injury Support Walk & Roll-a-thon
Saturday, October 2, 1999 AT Almaden Lake Park, San Jose, CA
Registration: 9:00 am Walk-Roll-Run: 10:00-11:30 am

See you there! ■

"Brain Matters"

Community Educational Events

Due to an overwhelming response to the **Claudia Osborn** talk last February, a series of community events entitled "Brain Matters" has been planned. These will occur approximately 3-4 times a year and will cover such topics as relationships, disability rights, and other educational issues presented by a variety of speakers.

Our first speaker, **Harriet Zeiner, Ph.D.** will present "Relationship Issues with Adults with Brain Injury" on Wednesday, October 13, 1999 at 5:30 pm.

The events will be held in San Jose at Del Mar High School, 1224 Del Mar Ave., San Jose.

If you would like more information, have a topic you would like addressed, or would care to help sponsor the series, please send an email to marylou@tbi-sci.org, or call (800) 352-1956 x 13. In the meantime, stay tuned... ■

FEATURED STAFF

Mary Lou: A "Resourceful" Person

This issue's spotlight is on **Mary Lou Gustafson**. Mary Lou joined the TBI-SCI Grants in 1997 and recently assumed a Research Associate position



Mary Lou Gustafson

with the TBI Grant. She conducts interviews on past Santa Clara Valley Medical Center inpatients with traumatic brain injury,

responds to requests for information regarding TBI resources, and coordinates quarterly community education events.

Mary Lou loves talking with people out in the community and receiving emails from all over the world. It has been especially exciting interviewing former patients at ten years after their injury.

Mary Lou graduated from North Park University in Chicago, Illinois with a Bachelor of Science in Nursing. She went on to work at Evanston Hospital for five years and then as Head Nurse at an HMO clinic for Rush Presbyterian St. Luke's Hospital. Upon arriving in California, Mary Lou took some business courses, which allowed her to work first supporting various physicians at SCVMC and then at home doing medical transcription while caring for her adopted son, **Michael**, who has disabilities.

Mary Lou enjoys reading, traveling, playing the piano, church, attending sporting events, the Internet, and spending time with her son and special friends. She loves to have the last word, especially with punning. Here at the Grants it is now o-pun season. ■

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 **Robin Morgan**, (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 **Robin Morgan**, (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 Friday of the month from 12:00 P.M. to 2 P.M. Contact **Janie Whiteford**, (408) 295-9896, x42, for the location. ■

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There have also been some changes at our outpatient facility as well. **Kazuko Shem, MD** has been appointed as SCVMC's Outpatient Spinal Cord Injury Specialist and **Nancy Jorgensen, RN** is the Outpatient Clinic's Nurse Practitioner. The outpatient clinic is equipped to deal with medical issues, equipment issues, mobility problems, sexuality issues, pain management, and more! The clinic recently established a toll-free number for patients to call for information and appointments (800) 314-4611. ■

SCI Research Organizations

Recently, there has been a flurry of interest in curative and regenerative research. Listed below are several research organizations, as well as website references that may be helpful for those interested in obtaining information on what's new in the research arena.

Acorda Therapeutics

15 Skyline Drive
Hawthorne, NY 10532
(914) 347-4300
www.acorda.com

American Paraplegia Society

75-20 Astoria Blvd.
Jackson Heights, NY 11370
(718) 803-3782
www.apssci.org

American Spinal Injury Association

345 E. Superior St. Room 1436
Chicago, IL 60611
(312) 908-6207
www.asia-spinalinjury.org

Center for SCI Research

Craig Hospital
3425 S. Clarkson Street
Englewood, CO 80110-2899
(303) 761-5281 (303) 789-8490
www.craig-hospital.org/rehab/

Christopher Reeve Paralysis Foundation

(800) 225-0292
www.apacure.com

CORD - Collaboration on Repair Discoveries

University of British Columbia
2329 West Mall
Vancouver RC V6T 1Z4, Canada
(604) 822-2211
www.cord.ubc.ca

Karolinska Institute

P.O. Box 200 SE-171 77
Stockholm, Sweden
www.mic.ki.se

Kent Waldrep National Paralysis Fndtn.

16415 Addison Rd. Suite 550
Addison, TX 75001
(877) SCI-CURE
(972) 248-7100
www.kwnpf.org

Paralyzed Veterans of America

SCI Education and Training Fndtn.
801 Eighteenth St. NW
Washington, D.C. 20006
(202) 416-7655
www.pva.org

The Miami Project to Cure Paralysis

Univ. of Miami School of Medicine
1600 N.W. 10th Ave. R-48
Miami, FL 33136
(305) 547-6001
www.miamiproject.miami.edu

Spinal Cord Research Centre

University of Manitoba
436 Basic Medical Sciences Building
730 William Ave.
Winnipeg, Manitoba R3E 3J7, Canada
www.scrs.umanitoba.ca

Spinal Cord Society

Wendell Rd.
Fergus Falls, MN 56537
(218) 739-5252
(218) 739-5261
members.aol.com/scsweb/private/scshome/html

Reeve-Irvine Research Center

Sharon Rossie
University of California, Irvine
University Advancement
4900 Berkeley Place
Irvine, CA 92697-5605
(929) 824-1379
www.reeve.uci.edu/~reeve

SCI Research Related Websites:

www.spinewire.com
www.cureparalysis.org

Neuro-Venture Forum, Nov. 15, 1999

One day conference provides the opportunity to learn about the latest in the field of neural repair research and meet leaders in the field of neuroscience. Friday, Nov. 15, 1999, from 8:30am to 4:30pm at the San Francisco Airport Marriott Hotel.

For more info contact: 1-877-NVFORUM. ■

Follow-up study of individuals with high tetraplegia (C1–C4) 14 to 24 years post-injury

Karyl M. Hall, Susan T. Knudsen, Jerry Wright, Susan W. Charlifue, Daniel E. Graves, Peter Werner.

An injury to the spinal cord at the levels of the first through fourth cervical vertebrae results in a condition called high tetraplegia. An individual with high tetraplegia loses the ability to move the trunk, arms, and legs, has problems speaking, and has great difficulty breathing, in some cases needing a ventilator to stay alive; a person who is very well-known with this kind of injury is **Christopher Reeve**.

With such severe injuries, it used to be common for most of these individuals to die soon after their injuries; however, with current medical technology, the life span for people with high tetraplegia has increased substantially. Along with the increased life span have come questions about quality of life; issues concerning mobility, interaction with others, attendant care, satisfaction with life, and self-esteem.

This study was the third phase of a study that initially, in 1984, examined individuals with high tetraplegia who were 1 to 11 years post-injury. These subjects were recruited from either Santa Clara Valley Medical Center in San Jose, California, Craig Hospital in Englewood, Colorado, or The Institute for Rehabilitation and Research in Houston, Texas. In the second phase, 1992–1994, these people were con-

tacted again; they were now 10 to 21 years post-injury. In phase three, the individuals were 14 to 24 years post-injury. In the current study, those people with high tetraplegia that were ventilator-assisted (VA) were compared to those that were ventilator-independent (VI) on quality of life measures. The belief was that the VA group would have a lower quality of life due to the increased medical care, complications, and mobility difficulties that come with using a ventilator.

What was found was that the VA group needed more specialized attendant care (e.g. RNs and LVNs), more hours of care per day, and had more paid attendants over the year than the VI group. This was probably due to the increased medical requirements surrounding the use of a ventilator. However, there were important similarities between the two groups. The VA group reported being out of the house for the same number of days per week as the VI group. When asked “are you glad to be alive?” 88% of the

VA group and 94% of the VI group responded “yes.” Similarly, 69% of the VA group rated their quality of life as “good or excellent” compared to 75% of the VI group. In terms of self-esteem, both the VA and VI groups had the same average score (29/36) on the Rosenberg Self-Esteem Scale.

Overall, all of the indications of quality of life were high for both individuals with VA and VI despite the substantial physical limitations of the groups. This suggests that even with an injury as severe as high tetraplegia, people are able to make adjustments and live a happy and fulfilled life.

If you want to read about this study in more depth, it will be published in the Archives of Physical Medicine and Rehabilitation within the next few months. Support for this project came from the U.S. Dept. of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research, Grant #H133N50003. ■

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INTERACT

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