NEW DIRECTIONS

A NEWSLETTER FOR INDIVIDUALS AND FAMILIES WHO HAVE EXPERIENCED BRAIN INJURY

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Funding for the Research and Training Center and *New Directions* Newsletter Comes to a Close

Our current grant through the National Institute on Disability and Rehabilitation Research for the RRTC in Rehabilitation Interventions following Traumatic Brain Injury came to a close August 31, 2004. It has been a wonderful experience serving you, the readers of New Directions, over the last 5 years. We thank all of you for being faithful readers and we appreciate the support, feedback and ideas you have given us. In addition, we would like to thank NIDRR for their support. The Training staff of our RRTC would like to thank all of you for the opportunity to serve:

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ARE YOU A FAMILY CAREGIVER?

Caregivers are relatives, friends or neighbors who stand by their loved ones as they face chronic illness or disability. Caregivers are a diverse group of people of all ages and from all walks of life who share a common bond of helping others. Caregivers are special people who often receive little recognition and thanks for their efforts.

If you recognize yourself in this description, then the National Family Caregivers Association (NFCA) may be just what you are looking for. NFCA is a grass roots organization created to educate, support, empower and speak up for the millions of Americans who care for chronically ill, aged or disabled loved ones. NFCA is the only constituency organization that reaches across the boundaries of different diagnoses, different relationships and different life stages to address the common needs and concerns of all family caregivers.

Through its services to members in the areas of education and information, support and validation, public awareness and advocacy, NFCA strives to minimize the disparity between a caregiver’s quality of life and that of mainstream Americans.

Current services of NFCA include:

- a newsletter providing "can do" information , resources and questions and answers
- a caregiver-to-caregiver support network to help caregivers find a friend in similar circumstances
- cards for caregivers that provide a different upbeat message three times a year to remind caregivers they are not alone
- The Resourceful Caregiver, NFCA’s guide to helping caregivers take charge of their lives
- the NFCA speaker’s bureau whose members educate and inform professionals and caregivers from coast to coast
- the NFCA Caregiver Member Survey Report that documents and validates the commonalities of the caregiver experience
- National Family Caregivers Week Celebrations to raise public awareness and caregiver consciousness

For more information or to receive a membership packet contact:

National Family Caregivers Assn.
10400 Connecticut Avenue, #500
Kensington, MD 20895-3944
800.896.3650 (ph) or
301.942.2302 (fax)

E-mail: info@nfcacares.org
Web site:
http://www.nfcacares.org

How to Form a Support Group for Families of Adults with a Brain Injury

Support or "self-help" groups are formed by individuals who share common concerns. The groups may be participant-initiated or provided by a health care institution, social services agency or nonprofit organization or church.

The purpose of the support group is to allow persons who are facing the difficult task of daily caregiver to benefit from interaction and support from other people in a similar situation.

A degenerative or terminal illness or an accident involving a family member is a traumatic experience for spouse, parents, children and other relatives. A support group may work towards mutual problem-solving, coping mechanisms, dealing with grief and sharing information. Some communities have a network of established support groups; others may have few or more. The following guidelines will assist family members or caregivers interested in forming a support group.

Guidelines for Establishing a Family Support Group: **Getting Started**

- ◆ Determine the focus of the group (i.e. family members of TBI consumers).
- ◆ Establish a contact person whose phone number can be used.
- ◆ Enlist the help of other families in a similar situation, if you know any.
- ◆ Seek assistance from medical experts, social workers, or other clinicians who can provide consultation and meeting space, give presentations or facilitate meetings. Good initial contacts may be obtained from existing support groups, nursing homes, hospitals, family physicians, neurologists, counseling and home care agencies, Adult Day Care programs, senior centers, and local branches of national organizations such as the Brain Injury Association (formerly the National Head Injury Foundation). Make sure to leave your name, address, and phone number when contacting professionals or agencies so that they can make referrals to your group.

- ◆ Plan a time, place and agenda for the first group meeting.
- ◆ Advertise the group by distributing press releases to local newspapers and by posting announcements on community bulletin boards in churches and synagogues, libraries, clinics and senior centers. You may want to design an eye-catching flier.
- ◆ Try to get a human interest story into the media to help focus community awareness on the problems and to locate families in need of support.
- ◆ Talk to local radio and TV stations. You can submit 30-second and one-minute public service announcements which are typewritten. There is no charge for nonprofit organizations. Announcements should describe the nature of the support group, the time, place and phone contact for meetings.

Structure, Goals, Objectives and Group Process

The group must determine certain procedural and philosophical matters, including:

- How often should the group meet?
- What times are convenient?
- Is the meeting site accessible?
- Who will lead the sessions? (It is helpful, especially in the beginning, if a professional can lead the group or at least make a presentation.)
- Discuss with other participants what they want to get out of the group and how participants might help one another.
- Plan long-term goals. Will the group be used as a vehicle to promote public awareness, to seek out isolated individuals who might like to participate, or will the group concentrate on building rapport among a tight-knit group of members?
- Plan future agendas: Local agencies, national organizations, universities, and public libraries are all potential sources of information. There may be books, films, video tapes, and research articles available for loan that can be shared with the group and/or used as a topic of discussion.

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Brain Injury Association of America: Support for Survivors and Families

Individuals with brain injury and their families need plenty of support from those who really understand. But where to look? Chapter affiliates of the Brain Injury Association of America may be part of the answer.

Nearly every state has an active affiliated chapter of the Brain Injury Association of America (BIAA). The primary aim of the BIAA, its chapters and affiliates is to promote public awareness of and education about brain injuries.

The association also encourages injury prevention programs and advocates improved medical and rehabilitation services.

Since it began in 1982, the Brain Injury Association of Texas (BIATx) has answered thousands of requests for information through its toll-free family help line. It has also hosted numerous annual conferences that brain together survivors, family members, and professionals to improve services to persons with brain injuries.

Support groups are vital links for survivors of brain injuries and their families. There are several over the state of Texas.

BRAIN INJURY SUPPORT GROUPS IN TEXAS

Austin

HealthSouth Stroke Survivor and Caregiver Support Group
Monica Fuentas
512.479.3691

McBeth Stroke Aphasia Club
Krisite Moreland
512.974.9015

Bryan

Ray of Hope Support Group
Denny or Jackie Crutcher
979.774.9230
rayofhope@iobv.com

Conroe

HealthSouth Rehab Hostpial
Barbara Loper
281.364.3386

Corpus Christi

Brain Injury of South Texas
Marcia Pilbin
361.241.3763
jpilbin250@aol.com

Edinburg

Neurocognitive Support Group
Dr. Cynthia Cavazos-Gonzalez
956.380.6550
neurorehabcenter@yahoo.com
www.neurorehabcenter.com

El Paso

El Paso Brain Injury Support Group
Barbara Redpath
915.851.2132
texas741@aol.com

Georgetown

Georgetown Hospital Stroke Support Group
Stephanie Chowing
512.930.4163

Houston

Texas Brain Injury Network
Cheryl Amoruso
281.997.2855
camoruso@pdq.net

Challenge Brain Injury Support Group
713.729.5162

Houston Center for Independent Living
Tony Koosis
713.974.4621

Memorial City Rehab Hospital Spring Shadow Pines
713.465.8563

Recovery Awareness Foundation
Paulette Keeney
281.583.0448

Hurst

Mid-Cities Acquired Brain Injury Family Support Group
Dr. Karen Brewer or Sue Stauffer
817.540.0861
harlansue@aol.com

Longview

Longview Brain Injury Support Group
Minette Hutchinson
903.753.5316
minhutch@aol.com

San Antonio

Alamo Head Injury Support Group
Evelyn Tattini
210.614.4323
etattini@alamoheadinjury.org
www.alamoheadinjury.org

DID YOU KNOW?

There are multiple web sites containing information on traumatic brain injury (TBI) and disability. The following is a partial list of sites you might find helpful. Many of these sites refer you to additional resources you may also find helpful. Phone numbers for some have also been included in case internet access is not possible.

The Brain Injury Association of America, www.biausa.org Be sure and check out their publication section as well as links and resources. **800.444.6443**

The Brain Injury Association of Texas, www.biatx.org , **800.392.0040**

The National Organization on Disability, www.nod.org offers answers to basic questions about disability. 202.293.5960

The Equal Employment Opportunity Commission, www.eeoc.gov has facts on employment and disability discrimination. **800-669-4000**

The Model Traumatic Brain Injury System project, www.tbindc.org has a newsletter called "Facts and Fig-

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Helpfull Web sites

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ures" with current and past issues available.

The Social Security Administration, www.ssa.gov has a great collection of their most frequently asked questions about forms, benefits, and conditions. **800-772-1213**

Traumatic Brain Injury Guide by Dr. Glen Johnson, Neuropsychologist, www.tbiguide.com, is an on-line book written for Dr. Johnson's patients that he now shares describing TBI in easy to understand language.

Independent Living Research Utilization (ILRU), www.ilru.org, a national center for information, training, research, and technical assistance in independent living. **713.520.0232**

THE NATIONAL DATABASE OF EDUCATIONAL RESOURCES ON TRAUMATIC BRAIN INJURY

Looking for videotapes or written information on brain injury but finding it hard to know where to go? The National Database of Educational Resources on Traumatic Brain Injury is available to help you. The database is a project of the RRTC on Rehabilitation Interventions following Traumatic Brain Injury at TIRR This database contains information on over 400 videos, booklets, pamphlets, and manuals developed around the country and addressing a wide variety of subjects. A few of the subjects are:

- Diagnosis and Medical Management,
- Cognitive and Memory
- Functioning, Education/School,
- Return to Work, and
- Computers and Adaptive
- Equipment.

The database can be found on the world wide web at www.braininjuryresearch.org . If you do not have access to the internet, you may call or write and request a FREE database search on two subject areas of your choice. The phone number is 713-797-5947 and the address is TIRR Library, 1333 Moursund, Houston, TX 77030-3405. You will receive a printout with a title, address, phone number, brief description, cost and year produced for each resource that matches your request.

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TIRR (The Institute for Rehabilitation and Research)
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