

The **ALS** UNIVERSITY OF **Miami** *ALS Center* Newsletter

Volume 6 • Issue 3 • Spring 2005

The official newsletter of the University of Miami ALS Center

Kessenich Corner

Several companies provide help to elderly people or have any kind of disability to receive either care or financial help

The Alliance for Aging has been administering the Elder Helpline in Miami-Dade County under Title III-B of the Older Americans Act since February 1, 1995. We started serving as the Elder Helpline for Monroe County January 1, 2002.

Elder Helpline

The Helpline is part of an information and referral network providing people with information, choices and opportunities. Its mission is to empower elders, their families and caregivers to make informed decision about aging in place, in an elder-friendly environment, with security, purpose and dignity. The Helpline is just the starting point for information and referral in your community. The role of the Helpline is to discuss your needs, find a program or service to meet those needs, and give you the information on how to get connected. Elder Helpline can help people with disabilities also. Elder Helpline specialists have a number of resources right at their fingertips, phone numbers of agencies, program descriptions and eligibility guidelines.

Call **1-800-96 ELDER (35337)**. Elder Helplines can be accessed through the Florida Relay Service **1-800-955-8771** for TTD or **1-800-955-8770** for the voice impaired.

National Association for the Terminally Ill

National Association for the Terminally Ill patients is a 501c3 not-for-profit organization, whose purpose is to help the children and families of those suffering from a terminal illness. They will help with financial assistance with living expenses, such as:

- telephone bills,
- home/auto repair,
- electric bills,
- rent or mortgage,
- grocery vouchers and
- medications.

It sounds too good to be true, but they help. You need to demonstrate that you have a terminal illness, must be a resident of the United States, but

you do not need to be citizen. The assistance may be requested for up to three months or 90 calendar days. At the end of this time if further assistance is needed, and additional request may be made.

For more information call **1-888-847-0390**

Broward County Elderly and Veteran's Service Division

The Veterans Services Section of the Broward County Elderly and Veterans Services Division offers veterans, widows and families of veterans, assistance in matters dealing with pension, compensation, education, insurance claims and other veteran benefits. It also provides case management services for homeless veterans. Emergency assistance and case management service programs are available to veterans and their families through these offices:

Ft. Lauderdale Office

2995 N. Dixie Highway, Ft. Lauderdale, FL 33334

Deerfield Office

1600 W. Hillsboro Boulevard Deerfield Beach, FL 33442

Hollywood Office

3550 Hollywood Boulevard, Hollywood, FL 33021

Community Care for the Elderly Veterans Section

The Community Care for the Elderly Section of the Elderly Services and Veterans Division provides case management and in-home supportive services to residents age 60 and over who are physically impaired or at risk of institutionalization.

To get an application for assistance call **(954) 537-2936**.

Every State has a Community Care for the elderly program.

Miami-Dade County Housing Agency

Miami Dade County provides financial assistance to eligible person(s) with disabilities for architectural barrier removal and essential home modifications to improve accessibility, safety and security as needed to maintain their independence. For instance, entry and access considerations, such as widen existing exterior and interior doorways, improve bathroom accessibility, improve kitchen accessibility, raise or lower outlets and switches to an accessible height.

For more information contact Miami Dade Housing Agency at (305) 250-5238 or DSAIL at (305) 547-5445

Broward County Community Development Division

The Community Development Division provides financial assistance for eligible elderly and/or disabled person(s) as defined under the State Housing Initiatives Partnership Program (SHIP) for barrier-free housing. State funds are available to those eligible homeowners and immediate family members living with these homeowners to pay for low cost essential housing modification and retrofitting to improve accessible, safety and security as needed by older and disabled persons to maintain their independence.

For more information contact SHIP housing coordinator, Broward County Community Development Division at (954) 765-4910 Ext 247

FAAST South Florida Regional Demonstration Center, Stein Gerontological Institute, Miami Jewish Home and Hospital for the Aged

FAAST seeks to enhance the quality of life for all Floridians with disabilities by promoting greater independence through the use of assistive technology

Residential Rehabilitation Program

The state of Florida provides funds to carry out a home improvement program. This assistance is limited to eligible homeowners and is based on income. At least 30% of the beneficiaries who receive assistance must have incomes at 50% of the median or less. The remaining households must have incomes 80% of the median or less. The maximum loan award is \$45,000.00 and is deferred over a period of ten years. For more information call (305) 883-5888

Community Development Block Grant

A major funding source for the City of Hialeah is the Community Development Block Grant Program. This Federal Housing and Urban Development Grants has the primary objective is to expand the supply of decent, safe, sanitary and affordable housing, as well as the creation of programs geared to assist low and moderate income families and individuals, augmenting and fostering economic growth. Through this program, the city has been able to create and strengthen linkages between all levels of government, the private sector, other non-profit and for profit agencies and organizations, thus maximizing existing resources. For more information call the city of Hialeah at (305) 883-8039.

Legal Services of Greater Miami

3000 Biscayne Blvd, Suite 500 Miami, Fl 33137
(305) 576-0080

Little Havana Activities and Nutrition Centers of Dade County

This center provides recreation and hot lunches to people over 60. They provide transportation from the patient's home to the center and classes of ceramic, English and painting are offered in the same location. For more information about this program call (305) 858-2610
700 SW 8th Street, Miami, Fl 33130

Miami-Dade Community Action Agency Meals for the Elderly Program

The mission of the Miami Dade Community Action Agency's Elderly Program Division is to enhance the quality of life of all elderly residents of Miami Dade County. Meals for the Elderly Program operates senior centers in Opa-Locka, Edison, Brownsville, Harry Cain Towers, Perrine, Goulds, Naranja, Florida City, Ives Dairy, Jack Orr, South Miami Senior Centers, Pine Wood Villas, Colonel Zubkoff and First United Methodist Church. Service includes meals, outreach, nutrition education and recreational activities. For information call (305) 347-4674.

Meals on Wheels, provides frozen meals to homebound elders and disabled adults in Downtown Miami, North Miami Dade and South Miami. Call (305) 347-4674

The Senior Companion Program provides part time volunteers who provide respite care and companionship to homebound patients. For more information call (305) 347-4654
395 NW First Street, Miami, Fl 33128

Action Community Center

They provide free transportation to patients with disabilities or the elderly. Just call four days prior to the appointment. Call at (305) 545-9298

Catholic Charities of the Archdiocese of Miami

They run 40 different programs for the elderly and disabled. For Catholic Home Health Services call (954) 486-3660 or (305) 278-0064
For Nutritional program call (305) 751-5203
Satellites office information call 1-866-758-0025
(954) 630-9404





Dr. Deborah Mash

The Importance of Organ Donation in ALS Research

Deborah Mash PhD, Spyros Papapetropoulos MD PhD, Walter G Bradley DM FRCP

Recent research suggests that at least in some patients ALS may be caused by toxins that may be naturally present in the environment. We have a research program that plans to collect tissues from patients with ALS to determine if this theory is correct. However, research into diseases of the nervous system like ALS is different from that involving other organs of the body, such as the liver, kidneys or muscle. It is possible to take samples of all those other organs to study them in the laboratory. We cannot take a sample of your brain or spinal cord without perhaps doing irreparable damage. For this reason, much research on neurological diseases needs public spirited patients to be willing to donate their brains for research when they die. For many such patients this nervous system donation is their way of fighting the disease even after their death.

We shall be offering information about nervous system donation to all our ALS patients. Your brain and spinal cord hold the answer to providing a cure for this terrible illness.

The University of Miami Brain Endowment Bank™ was founded in 1987. We work in conjunction with researchers from around the world, providing brain tissues to scientists who are investigating the underlying causes of brain diseases and the pathological changes that occur in the brain. The development of effective treatments and prevention strategies depends on the thorough understanding of these pathological changes in the brain. The Brain Bank includes tissues from normal individuals who have donated their brains for research, and also diseased brains from individuals with neurodegenerative and neuropsychiatric disorders.

It is important to understand that a brain and spinal cord autopsy will not interfere or complicate the family plans for a funeral, burial or cremation. Special arrangements are made by the Brain Bank staff to complete the brain autopsy as soon as possible after death occurs to maximize the brain tissue's research value. There is no cost for a brain donation. Reasonable costs incurred for transportation of the donor and other costs involving the analysis of brain tissue will be incurred by the Brain Endowment Bank™. Funeral arrangements remain the responsibility of the family.

Each brain and spinal cord donated to the Brain Endowment Bank™ is considered a precious and invaluable source of hope, and brain donors are visionaries. The important scientific work being done today would halt without the generosity and vision of the participants in our brain donor program.

If you would like to learn more about the research program in ALS involving nervous system donation please ask your neurologist or talk to one of our nurses, or call 305-243-7400 (1-800-690-ALS1 [1-800-2571]). If you would like to learn more about the University of Miami Brain Endowment Bank or to become a donor, please call 1-800-UM-BRAIN (800-862-7246).



To My Dear Family and Friends,

The sun has set on my earthly life, but because of our Savior and Lord, Jesus Christ, I have been reborn. I now have a new and perfect body—free from the ravages of ALS and free from anxiety and worry. Now I reside with the Lord in his heavenly home where I will live forever and ever knowing nothing but joy and peace. Thanks be to God for Jesus Christ who died for us, bearing the sins of the world upon his precious shoulders so that we may live eternally.

I hope I have made a positive difference in the many lives that I have touched over the past seventy-two years. Certainly I made many, many mistakes that I would rectify if I could. If I have hurt or disappointed you, I beg for your forgiveness. My journey through life has been long and varied as a husband; father, brother, teacher, and friend. Through it all, I have had a good life and the best part took place on May 28, 2000 when I was baptized at Tomoka Christian Church along with my beautiful wife Kathy. When I declared openly to the congregation that day that I accepted Jesus Christ as my personal savior and when Joe Putting emerged me into the water, the old Tom Davis died and the new one was born. The new Tom made many needed changes thanks to the guidance of Joe, my dear friend and pastor, and to you, my family and friends. I learned, perhaps for the first time, what it means to walk with the Lord and what it means to go forth and glorify the name of Jesus Christ through my actions and words. I later was diagnosed with ALS (Lou Gehrig's disease). Kathy and I were devastated by the news. What was I to do? I was always the athlete, the healthy person who had never been sick. Would I actually end up in a wheelchair unable to walk or talk? What would happen to Kathy, the love of my life? What in the world were we to do? I simply couldn't fathom it all. I didn't want anyone to know so I told Kathy that. Most of you know the rest of the story... Kathy said..."No way, Tom. We can't handle this alone and there is a reason why we have been given this heartbreaking news. On the contrary, we are going to tell everyone about your diagnosis and somehow we will turn something really bad into something good and meaningful." Subsequently, with God's help, we have done just that. We asked our Father in Heaven to provide guidance and to make us adequate for the challenges that lay ahead. You prayed for us too; you lay healing hands upon us; you brought us hot meals, sent loving cards and notes and bolstered our spirits in countless ways. You often were amazed at our strengths in the face of such adversity but Kathy and I knew full-well that our strength wasn't our own but came from the Lord.

You observed my body becoming weaker and weaker over the passing months and you didn't know what to do when I even lost my ability to speak. This perhaps was the toughest blow because I so enjoyed talking with you in person and on the phone. Bless your hearts; I knew you were suffering for me and you tried so hard to hide your sadness and discomfort over my plight. Kathy understood it all and was always able to help me gain renewed inner strength as the disease relentlessly pro-

gressed. She never let me give up. She made me reach deep inside myself to become the valiant fighter she is as she aptly manages her blindness with such self-confidence and grace. Most of all, Kathy's love and deep faith showed me how to trust in Jesus Christ with all my heart and to lean not on my own understanding. A real turning point for me was when Kathy had me sit with her and listen to "The Purpose Driven Life." As I listened to this amazing book I truly began to realize that my life on this Earth was simply a minute portion of my eternal life in Heaven. I realized utterly and completely that God alone had established the purpose of my life before I was born and I finally understood that Kathy and I had been chosen by God to embrace our mutual disabilities so that we could best affect the life of others through our devout faith and our personal examples. Oh yes, it became crystal clear and our walk with the Lord was such a gift from Him who knows all, and is all. I was no longer afraid of dying.

I asked you to pray for my Ormond Beach ALS Support Group where I was able to share mutually with my fellow Lou Gehrig's disease sufferers our fears, our camaraderie, our laughter and our tears. I love you all and I was blessed to have walked the walk with each of you. Keep up the good fight for I know there will be a cure someday. Bill Swan, what a joy you have been to me! I am counting on you to hang in there and keep the group laughing.

Do not mourn for me today my darling Kathy, my precious family and my cherished friends particularly Lorraine, Richard Charlie, Ron, Ray, Lynda, Carolyn, Phil, and Jesse. This is a day set aside to celebrate and to rejoice for I have been called home and I have been made whole again. Share your memories of me with one another, lift your voices in praise for my homecoming; if you weep, do so in joy and not in sorrow for when I took my last breath, the Vail was lifted and I was caught up in the loving arms of Jesus Christ. O happy day! Praise the Lord! I have been reunited with those I love who have preceded me in Heaven and the time will come when we too will be reunited in glory with our Savior and Lord never to be separated again. Some small part of me will be with you always when memories of our time together come gently into your hearts and minds.

My children know that you have made me proud and that I love you deeply. My brother, my sister, I thank you for our growing up years and for the love you have shown me. Threese, the mother of my boys, know that I so appreciate the role you have played in their lives and your love and concern for Kathy and me. My friends...students, teachers, tennis buddies and the like...you have touched me and I have grown through your influence. To my nurses, Beth, Richard, Deborah, Susie, Nancy, Fran, and May; you will never fully comprehend just how much your loyalty, comfort and devotion meant to me! You are among my most special angels and I thank you profoundly!

To my wife, best friend and #1 caregiver Kathy, I will be with you always for you are part of me and I am part of you. Now listen to Josh GroBin's beautiful song that says it all...

Your Thomas.

Coping and Quality of Life

Maria Zayas-Bazan, Psy.D.

ALS is an illness that has a profound effect on the individual afflicted with the illness and their loved ones. The illness taps into many factors affecting quality of life and may produce suffering. Suffering is a sense of brokenness or splitting apart that may be experienced as a split between the self and the now malfunctioning body, a sense of isolation from the community, and a sense of separation from the transcendent. It is important to distinguish between physical pain and suffering. Physical pain can be a major component of suffering, but suffering encompasses much more than physical distress and often occurs in the absence of physical pain.



Dr. Maria Zayas-Bazan

We all have a need for meaning and purpose in our lives. This is universal, it provides a sense of purpose and connection in people's lives, and can be lost in the midst of coping with illness. Most common sources of meaning are based on family, career, religious beliefs and philosophical

system of belief. This is how we define our lives and evaluate our self-worth. They provide connections with something larger than the person's own life.

To be satisfying and effective, a source of meaning must provide a sense of purpose, value, efficacy and self-worth. This is highly individualized and is essential for the physically ill person as well as their care takers and loved ones. When sources of meaning are inadequate, it is important to enhance and strengthen the remaining sources of meaning, identify new sources that fulfill a sense of meaning, and explore with loved ones or professionals ways to identify a new purpose.

Changing your perspective is essential to improving coping skills. Acknowledge the roles that you continue to fulfill. These may be as a son or daughter, parent, friend or partner. These roles are accomplished just by your being there, in the moment, with your loved ones. Do not underestimate the positive effects of a warm glance, a caring smile, a light touch and a gentle kiss. Quality of life is related to a person's "spirit". ALS affects your physical abilities but, through acceptance of love and support, your spirit can continue to soar.



2004 Annual ALS Symposium

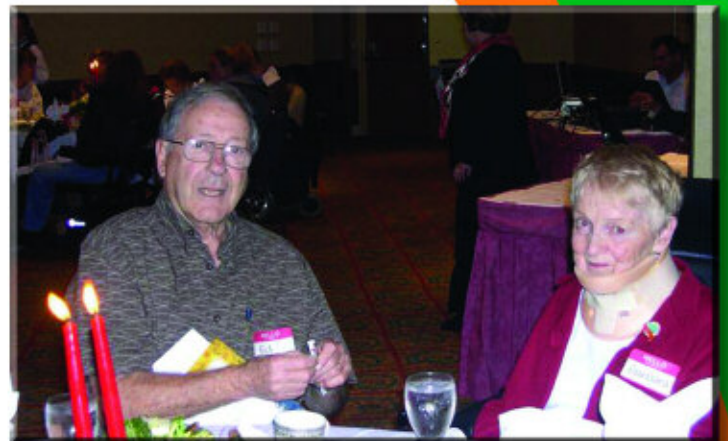
On behalf of the Kessenich Family MDA ALS at the Miller School of Medicine, we would like to thank our patients, guests, sponsors, speakers, staff and volunteers for coming together and participating in the 2004 Annual ALS Symposium held at the Radisson Mart Plaza. We greatly appreciate and acknowledge our sponsors for donating the time and efforts to support such a great cause especially Ramon Antelo from the Radisson Mart Plaza.

We would like to give thanks to Aventis Pharmaceutical, Inc. supplier of Rilutek®; Sandy Turnauer of Accredo Therapeutics; Lissette Gonzalez of Comprehensive Healthcare Services, Inc.; Carmen Kaifer and Doe Rubino of Pfizer- Alta Pharmaceuticals; and a special thanks to Hector Izquierdo of Medical Decision Services, Inc. for their generous contribution in providing our 2005 calendars. It was a pleasure having you participate and convey your suggestions based on your long years of experience. Your recommendations were extremely helpful for our patients and caregivers. Our staff and patients also recognize all the companies mentioned above for supplying medical services and/or equipment always in a prompt and professional manner and hope that we can continue to count on their support in the future. We would also like to kindly acknowledge all of our sponsors for presenting current information about new technology, medication and a variety of techniques available to improve the quality of our patients battling with ALS.

At this symposium, we had the pleasure of having Dr. Ashok Verma discussing Nutritional Support in ALS; Maria Zayas-Bazan, PsyD speaking about coping and quality of life; Sylvia Casabianca, REIKI Master, sharing techniques used in Alternative Medicine; Dr. Carlos Vargas informed us on early implementation of the peg tube and we also had a special presentation by Reverend Gabriel Ghanum on the spiritual aspects of coping with illness, primarily ALS. Finally, we obtained a vast amount of input on remarkable new studies and current findings regarding ALS and other related aspects of the disease. Dr. Walter Bradley revealed the latest updates from the International Symposium held in Philadelphia, PA and replied to many inquiries presented by guests, patients and caregivers concerning ALS.

Last, but certainly not least, we would like to thank The Kessenich Family staff and volunteers. The dedication and efforts put forth to make the necessary arrangements and successfully carry out the labor behind this annual event is a magnificent demonstration of caring, enthusiasm and commitment. We are delighted to have these individuals working continuously in cooperation with our sponsors to present all of our patients and caregivers with an opportunity to become informed about new technology, keep up with current research and studies on ALS; and, undoubtedly, maintain and strengthen the spirit of hope.

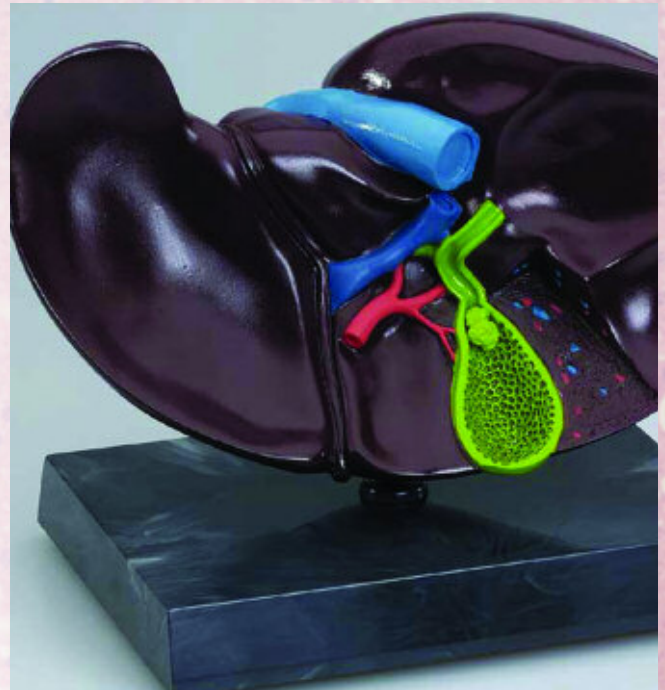




Indication of Liver Function Test for patients taking Rilutek

Rilutek should be prescribed with care in patients with current or history of abnormal liver function indicated by significant abnormalities in serum transaminase (ALT/SGPT; AST/SGOT). Frequently, ordered LFTs include ALT/AST which are found in the liver and are intracellular enzymes. These enzymes are released into the blood when there is serious damage or tissue cell death. Therefore, baseline elevation of several LFTs should exclude the use of Rilutek. It is recommended that a liver function test be measured before and during Rilutek therapy. Serum enzymes should be evaluated every month during the first 3 months of treatment, every 3 months during the remainder of the first year and periodically thereafter. For patients who develop elevations, more frequent testing should be done.

Avoid alcohol and tobacco while you are taking Rilutek. They can increase the risk of getting liver damage. Cigarette smoke can affect the amount of Rilutek in your body.



PEG Tube Precautions

For accidental tube removal or dislodgement, call your doctor immediately or go to the emergency room as soon as possible for tube replacement. The opening of the PEG site starts closing within the next 24 hours.



This picture is showing skin local infection. Cleaning is very important to maintain the skin intact and to avoid leakage from the tube. Do not be afraid to clean the area, you can shower and put soap and plenty of water.



In this picture you can see a very old PEG that needs to be replaced. In order to avoid this, flush the tube with seltzer water or coca-cola once a week. Make an appointment to see your gastroenterologist before the tube starts leaking or the tube blockage begins.

Memorial Ceremony

Saturday, February 11th started out beautifully at Oleta River State Park. It was a clear, breezy and sunny day. Our patient families began to arrive and place the pictures of their loved ones who had passed on. They placed them on a dedicated table our staff members set up for them. At about 12:15, the North Miami Beach Senior High School JROTC performed an exceptional Color Guard Presentation. Mr. Paul Martin provided the music throughout the event. The memorial service began with moving prayers by Reverend Gabriel Ghanoum, Mrs. Lourdes Grenier and Reverend Lois Murray. Our Special Dedication ceremony was led by Reverend Gabriel Ghanoum, which gave our family members and friends an opportunity for spiritual reflection. In the second ceremony everyone gathered in a circle and released twelve white doves in great signifying that even though their loved ones are not present with them today, they will forever live in their hearts and memories. In closing everyone enjoyed a delicious lunch provided by Shorty's Bar-B-Q and ended with the sharing of many fond memories.

We would like to give thanks to our sponsors, Vitas Hospice Care, Rehabilitation Center of Miami, Florida Professional DME, Support Care Group and Care Force Home Health agency. We greatly appreciate and acknowledge our sponsors, as well as the Kessenich Family staff and volunteers for donating their time and efforts.



Chicken and Rice

Ingredients:

- 1 1/2 cups of minute rice.
- 1 can cream of mushroom soup.
- 1 can cream of celery soup
- 1 cup milk
- 8 chicken breasts, skinned and chopped in blender
- 1/2 package dry onion soup mix.

Procedure:

- 1) Mix rice, cream of mushroom soup, cream of celery soup and milk in 9 X 13 inch casserole.
- 2) Layer chicken and dry onion soup mix over rice mixture.
- 3) Bake tightly covered for 2 hour at 350 degrees.



Creamy Banana Pudding

Ingredients:

- 3 cups milk
- 3 large egg yolks
- 1/3 cup honey
- 3 tablespoons cornstarch
- 1/2 teaspoon vanilla extract
- few grains of salt.

Procedure:

- 1) Put all ingredients except bananas in a 3-quart saucepan and whisk until thoroughly blended.
- 2) Stir 6 to 7 minutes over moderate heat, until mixture thickens and comes to a boil.
- 3) Reduce heat to low and cook for 1 minute stirring constantly.
- 4) Remove from heat and stir in bananas
- 5) Serve warm or chilled.

Announcement

ALS Advocacy Day

Washington May 9-11, 2005

ALS Recovery Foundation

Walk-a-thon, Nov. 5, 2005

We would like to congratulate Robert Fernandez, our Clinical Secretary on the new addition to his family. Christy Fernandez born 1-11-05. Great Job!



Important Numbers

Kessenich Family MDA ALS Center	305-243-7400
.....	1-800-690-ALS-1
.....	www.miami-als.org
Muscular Dystrophy Association (National Patient Information)	1-800-572-1717
.....	www.mdausa.org
• St. Petersburg	717-576-5202 or 1-800-393-8552
• Palm Beach Gardens	561-242-5084 or 1-800-289-0535
• Miami	305-717-9937 or 1-800-572-0085
• Broward	(954) 757-4357 or 877-970-9696
ALS Association	1-800-782-4747
• ALS Association in Florida	1-888-257-1717
.....	www.alsa.org
National Caregiving Fdn	1-800-930-1357
National Family Caregivers Assn	1-800-896-3650
.....	www.nfcacares.org
Foundation for Hospice and Homecare	202-547-6586
National Hospice Org.	1-800-658-8898
A.D.E.L.A. Asociación Española de Esclerosis Lateral Amiotrófica	www.advernet.es/adela/index.htm
Social Security Online	1-800-772-1213
.....	www.ssa.gov
The Feeding Gastrostomy Information:	www.iinet.net.au/~scarffam/gtube.html
ALS Digest (Bob Broedel): To subscribe, please e-mail to	bro@hucy.mct.fsu.edu

If you need a referral to one of our satellite centers, please call 305-243-7400 or 1-800-690-ALS1.

NOTES:

*** We are seeking volunteers to assist in running the ALS Center and to assist patients and families at home. Please call 305-243-7400. This could be a health care professional or even a family member who has had experience with ALS patients and now has time to volunteer.**



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ALS Center**
1150 N.W. 14th Street (M-712)
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Miami, Florida 33136

ALS Support Group Dates For The Year 2005

Calendar

- Saturday, April 9
- Saturday, May 14
- Saturday, June 11
- Saturday, July 9
- Saturday, August 13
- Saturday, September 10
- Saturday, October 8
- Saturday, November 12 (Thanksgiving Luncheon)
- Saturday, December 10 (Annual ALS Symposium)



The ALS support groups will be held from 12:00 p.m. to 1:30 p.m. at the University of Miami Hospital and Clinics, 1475 NW 12th Avenue, Room #1301.

We hope to see you at the meetings where we will have different healthcare companies and providers monthly, which will give demonstrations of their newest products and services.

*The above dates are subject to change and in the event of rescheduling, we will inform you via mail. Please call Ginna or Graciela at (305) 243-7400 if you have any questions, or you can visit us at www.miami-als.org.

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