



**The Kessenich Family
MDA ALS Center**
3222-D Commerce Place
West Palm Beach, FL 33407

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ALS

Kessenich Family MDA ALS Center Newsletter

Volume 2, Issue 2

Summer, 2000

THE KESSENICH FAMILY MDA ALS CENTER

UNLOCKING THE GENETIC CODE

**By: WALTER G. BRADLEY, D.M.,
F.R.C.P. - Medical Director,
Kessenich Family MDA ALS
Center.**

The recent announcement of the decoding of 90 +% of the genetic code is very important. However, what has been achieved is only a first step to knowing what the genes do.

The DNA can be likened to the roads in a country. Many of those roads only have houses (or genes) on a small part of them. What has been done so far, for the majority of genes, has been to find what are houses, i.e. their addresses, and what is road without houses. We are now in command of about 90% of the addresses, and have the outline of the shape of those houses but we still have no idea who lives at the addresses. Of the perhaps 50,000 - 100,000 genes, we currently know the function (i.e. the protein produced and its role in the body) for perhaps 3,000 genes. The majority of genes discovered by the research project into the genetic code are completely unknown with regard to their function. Now begins the hard work of finding which of the genes relates to a given function in a cell, and to a given disease.

Nevertheless, the complete recognition of all the genes is a major step forward, for it will greatly speed up the search for the genes responsible for each disease, including the 80% of cases of familial ALS that is not due to mutations of the SOD1 gene. It will perhaps also allow us to recognize the multiple genes that predispose to sporadic (ie non-inherited) ALS.

NEW FACES AT KESSENICH CENTER

We have new faces around the clinic. Grosbyn Romero (G.R.), joined the Kessenich Family MDA ALS Center as a Sr. Staff assistant and he dedicates half of his time to the different activities of the center. Welcome GR.



Aventis Pharmaceuticals has a new sales representative for Rilutek in South Florida. Her name is Jennifer Wolfinger. Her role is to promote Rilutek and to be a resource to the ALS community. We welcome her and we give her our support.

DOCTOR'S CORNER

DIETARY FIBER

Importance of Fiber in the Diet

Dietary fiber, also referred to as "bulk" or "roughage", is the part of plant food that cannot be broken down or digested by the body. Dietary fiber helps maintain bowel health and regularity in

many ways. It helps maintain normal bowel function by nourishing colonic cells, supporting growth of healthy bacteria in the gut, increasing stool bulk, and slowing the absorption of simple sugars from the diet. In addition, The National Dietary Guidelines recommend a diet rich in fiber to help reduce the risk of certain chronic diseases.

Most healthcare professionals would agree that maintaining adequate dietary fiber intake is an important part of a healthy diet, and is a safe and natural way to promote and maintain regularity. While the American Dietetic Association (ADA) and the National Cancer Institute (NCI) have recommended that adults consume 20-35 grams of fiber per day, most Americans consume on average only 11-15 grams per day. For many people, simply increasing their intake of fruits, vegetables and whole grain foods is adequate to boost their fiber intake to recommended levels.

Although adequate fiber intake can be promoted by encouraging the consumption of a mixed diet including whole grains, fruits, and vegetables, factors including poor dentition, chewing and swallowing problems, diet restrictions and other health factors may interfere with consumption of a fiber rich mixed diet. In such cases, the most effective way to ensure adequate fiber in the diet is to include a dietary fiber supplement such as Benefiber.

Refer to volume 1. Issue 4 for Bowel Movement Management.

CALENDAR

SUPPORT GROUP DATES

Saturdays, July 8, 2000
August 12, 2000
September 9, 2000
October 14, 2000
November 11, 2000
December 9, 2000

Location: University of Miami
Hospital and Clinic, Room 1301
1475 N.W. 12th Ave., Miami 33136

Time: 12:00 m. - 1.30 p.m.
POC: Ginna Gonzalez
Phone: (305) 243-7400

SECOND ANNUAL GALA

November 2,000
To be announced

WALK - A - THON
for ALS
May, 2001

Looking for Volunteers

**11th International
Symposium on
ALS / MND
6-8 November 2000
Aarhus, Denmark**

**Yesterday
is a
cancelled
check**

**Tomorrow
is a
promissory
note**

**Today
is the only
cash you
have so
spend it
wisely**

"Kay Lyons"

Fiber Content of Selected High Fiber Foods

Cereals	Serving Size	Total Dietary Fiber (g)
40% Bran	1 cup	6.9
100% Bran	1/2 cup	10
All Bran	1/2 cup	15.3
Bran Chex	1 cup	7.9
Bran Flakes	3/4 cup	4.6
Cheerios	1 cup	2.6
Fiber One	1/3 cup	14.3
Frosted Mini Wheats	1 cup	5.9
Granola	1/2 cup	6.4
Nutri Grain, Wheat	100 g	6.3
Oatmeal,cooked	3/4 cup	3
Raisin Bran	1 cup	8.2
Shredded Wheat	1 Large biscuit	2.5
Wheat Chex	1 cup	4.0

Breads and Starches

Brown Rice	1 cup (cooked)	3.5
Egg Noodles	1 cup (cooked)	1.8
Oat Bran Muffin	1	2.6
Popcorn	3 cups (cooked)	3.3
Rye Krisp	1 wafer (triple cracker)	4.1
Whole Wheat Bread	1 slice	2.0
Wild Rice	1 cup (cooked)	3

Fruits

Apple, with skin	1 medium	3.7
Applesauce	1 cup	2.9
Bananas	1 medium	2.8
Fruit Cocktail	1 cup	2.4
Mandarin Orange, canned	1 cup	1.8
Oranges	1 medium	3.1
Peaches,canned	1 cup (halves or slices)	3.2
Peaches, fresh	1 medium	2.0
Pears,canned	1 cup (halves)	4.0
Pears, fresh	1 medium	4.0
Raspberries, fresh	1/2 cup	4.2
Strawberries, fresh	1 cup, whole	3.3

Vegetables

Broccoli, fresh	1 large spear	4.5
Broccoli, frozen, cooked	1/2 cup	2.2
Brussel Sprouts, frozen, cooked	1/2 cup	3.2
Carrots, canned	1/2 cup slices	2.2
Carrots, fresh	1 medium	1.8
Coleslaw	1 cup	1.8
Corn, canned	1/2 cup	1.6
Green Beans, canned	1/2 cup	1.8
Peas, canned	1/2 cup	4.0
Potatoes, mashed, dehydrated	1/2 cup	2.4
Potatoes, with skin	1	2.3
Spinach, canned	1/2 cup	2.5
Sweet Potato, canned	1 cup	3.4

Legumes, Beans

Baked Beans, canned	1/2 cup	6.3
Kidney Beans	1/2 cup	4.5
Lima Beans, canned	1/2 cup	4.5
Navy Beans	1/2 cup	5.8
Pinto Beans	3 oz	8
Split Peas	1/2 cup	8.1

Source of data, USDA Nutrient Database for Standard Reference, Release 12 (March, 1998)

Dietary Fiber Supplements

Benefiber Powder	1 Tbsp	3
Benefiber Juice Drink	1/2 cup	3

PATIENT CORNER

Veterans Benefits for Someone with a Diagnosis of ALS

The Veterans Affairs Hospitals offer many services that can be of great benefit to veterans with ALS. Every veteran with ALS should contact the VA and PVA (see below) to learn the details of the benefits available.

SERVICE-CONNECTED ELIGIBILITY:

If you were diagnosed with ALS while serving on active duty, or had symptoms and can prove you had muscle weakness within 2 years of discharge from active duty, you will be considered "Service-Connected" disabled for VA benefits. You could be eligible to receive maximum health benefits.

NONSERVICE-CONNECTED ELIGIBILITY:

If you cannot prove your ALS or muscle weakness occurred on active duty or within 2 years from discharge, you will be considered "Nonservice-Connected," but, depending on level of disability, still entitled to many health benefits as Category 4*** ("...determined by VA to be catastrophically disabled"). Your eligibility for benefits is also based upon discharge from active military service under other than dishonorable conditions.

Many ALS patients fall in to the non-service-connected category 4 and could and usually do receive: medications for \$2/month, head controlled highback reclining electric wheelchairs, electric beds, accessible environmental control panels, adaptive aides, money for home improvement accessibility changes, respite care, adult day care, and hospice care, communication equipment, prosthetic devices, canes, walkers, foot/ankle braces, etc. Eligibility for these and other benefits are dependent upon your level of disability and financial status. To obtain these and possibly more benefits, you must enroll in the VA Health system and

bring all your medical reports of diagnostic tests and examinations to prove you have ALS.

VETERANS HEALTH ADMINISTRATION (VHA) <www.va.gov>:

To receive health benefits from the VHA, you must first enroll to determine eligibility. You may do this at any VA hospital by completing an enrollment form and submitting your DD214 or honorable discharge certificate. You can also enroll online (some states are limited) at the website <www.va.gov> or over the phone by calling the VA Enrollment Service Center 1-877-222-VETS.

PARALYZED VETERANS OF AMERICA (PVA) <www.pva.org>:

This is an advocacy organization, chartered by Congress, to assist veterans with Spinal Cord Injury Disease (SCI/D) in receiving their VA benefits. Membership is free for veterans with SCI/D and includes assistance for receiving maximum VA benefits and medical care, prosthetics, home modifications, automobile adaptive equipment, monthly Paraplegia magazine, newsletters, support groups, participation in many disabled sports activities, and more. Call them at 1-800-424-8200.

*** The VHA system currently has 7 categories for priority of care. If you have nonservice-connected ALS with no disability, you will probably be rated category 7 and only be entitled to medication. As disability increases, you may be rated as high as a category 4, allowing for more home, respite, and equipment benefits. Please consult your PVA representative to assure that you are rated properly. If you want to participate in the ALS Gulf War Study contact ALS Association 1-800-782-4747

Prepare for your appointment by helping your doctor help you.

Open and honest communication between patient and doctor is vital, but



I SHOWED HER HOW TO USE THE INTERNET - SHE FOUND A JOB AT ANOTHER HOSPITAL THAT PAYS MORE THAN WE DO!

IMPORTANT NUMBERS

- Kessenich Family MDA ALS Center** **305-243-7400**
1-800-690-ALS1
www.miami-als.org
 - Muscular Dystrophy Association 1-800-572-1717
www.mda.org
 - St. Petersburg 717-576-5202 or 1-800-393-8552
 - Palm Beach Gardens 561-242-5084 or 1-800-289-0535
 - Miami 954-970-9696 or 1-800-572-0085
 - ALS Association 1-800-782-4747
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@huey.met.fsu.edu
- If you need a referral to see one of our satellite centers, please call at 305-243-7400 or 1-800-690-ALS1.

NOTES:

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

OTHER ANNOUNCEMENTS

Muscular Dystrophy Association Sponsored Kessenich Family MDA ALS Clinic

The Muscular Dystrophy Association (MDA) is a voluntary health agency and a dedicated partnership between scientists and concerned citizens aimed at conquering neuromuscular diseases that affect more than a million Americans.

MDA has the most comprehensive program of any voluntary health agency in the country. To be enrolled in our program a person must have one of our 40 covered neuromuscular diseases or a suspected diagnosis of such by their physician. As a member of MDA the following services are provided at no cost

1. Initial diagnosis visit and 4 follow-up visits at the clinic per year
2. MDA provides 1 physical, occupational, respiratory, and speech therapy visit per year
3. MDA provides \$ 2000 in the assistance of purchase of wheelchairs (adult-one every 5 years; child-one every 3 years) or leg braces
4. MDA provides \$ 300 per year for the repair of wheelchairs or braces
5. MDA provides a newsletter for individuals and their families affected by ALS, as well as a Support group (The Support group time and location to be announced)

MDA has recently hired Denise D. Castro as the Program Services Coordinator for ALS members and their caregivers. For the Kessenich Clinic assistance, questions, and to receive a packet of information, please contact her at 954 970-9696 or toll free at 1-877 970-9696. Please visit us at our website at www.mdausa.org

Muscular Dystrophy Association JERRY LEWIS, National Chairman.

Dedicated to the eradication of the muscular dystrophies, amyotrophic lateral sclerosis (Lou Gehrig's disease), myasthenia gravis the spinal muscular atrophies, Friedreich's ataxia and a host of other neuromuscular diseases.



Denise D. Castro

QUESTIONS AND ANSWERS:

many times it is difficult to remember key medical facts while sitting with your doctor, so plan ahead to be sure all the relevant facts about your medical condition are covered. Ten questions to review before going to the doctor are:

1. What is the purpose of this visit to the doctor?
2. What am I most worried or concerned about?
3. What do I most want help with now?
4. How have I been feeling? (Be specific, the doctor needs to know)
5. Have any new or unexpected symptoms occurred recently?
6. What is my current therapy (if applicable)? Have I been taking my medication as the doctor instructed? Have I missed any doses or taken them at irregular times?
7. Have I visited any other medical professionals in between visits (doctors, dentist, other)?
8. Have I required treatment in an emergency room or urgent care clinic? If yes, why.
9. Have I been diagnosed with another illness, or have I started any new medication (prescription, over-the-counter, or vitamin supplements)?
10. Have I had any major dental work done recently?

If you are visiting the doctor because you feel sick (rather than a regularly scheduled visit), or because you have an illness that you feel is getting worse, you may wish to review your health patterns. This will help the doctor identify what is making you feel sick or causing your illness to get worse.

Provided as an informational service from Partnership for care and Athena Rx Home Pharmacy.



Q. I am having trouble getting dressed, specially buttoning / unbuttoning my clothes. What type of dressing aids are there?

- A. • Buttoning device (Button Hook) (as you can see in the picture)
- Replace buttons with velcro closures
- Elasticized waistband

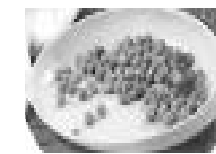


Q. If I have difficulty swallowing, what would be the best position while eating/drinking?

- A. Sit upright 45-90° angle (high fowler's position), head bent slightly forward (chin tuck)

Q. My food spills out of the plate. Is there anything that can help me with this problem?

- A. You can use plates with a curved inner wall in a slightly raised outer rim to help guide food onto your fork / spoon. You can also



adapt a plastic / metal plate guard or use a partitioned plate. For drinking purposes, cups with wide bases and

easy-to-grip handles. Look for wide, large - handle, light weight features in eating utensils.

You can make your own handle by wrapping a hand towel or a piece of cloth around the utensil's handle and wrapping some heavy duty tape (e.g. duct tape) around towel.



Refer to volume I, Issue 3 Newsletter for more information about assistive equipment.

MY BOOK OF RECIPES

Easy Chicken Treat

- 3 cups cooked chicken, finely chopped in blender
- 2 cups milk
- 1 can cream of chicken soup
- 1 can cream of mushroom soup
- 1 small onion, minced
- 1 cup Velveeta cheese, diced
- 1/2 cup green pepper, minced
- 1/2 cup celery, very finely chopped

Combine all ingredients in baking dish, cover and chill overnight. Bake at 350 degrees for 1 hour. Makes 4 servings.



Rice Pudding

- 1 tablespoon cornstarch
- 1 1/2 tablespoons honey
- 1 egg, beaten
- 1 cup milk
- 1/2 cup rice, well cooked
- 1/2 teaspoon vanilla

Blend first three ingredients in saucepan until smooth. Add milk slowly, stirring to mix well. Add rice. Cook over medium heat, stirring constantly until mixture is thick and comes to a boil. Remove from heat, add vanilla and cool. Sprinkle with cinnamon and nutmeg, if desired. Serve warm. Makes 4 servings.

SOME PEOPLE CHANGE JOBS, SPOUSES, AND FRIENDS

BUT NEVER THINK OF CHANGING THEMSELVES

"Paula Giddings"

We've Moved

EFFECTIVE MAY 23, 2000

Muscular Dystrophy Association

**3222-D Commerce Place
West Palm Beach, FL 33407**

Phone: (561) 242-5084 / 1-800-289-0535

Fax: (561) 471-1514



post card

MDA covering the Palm Beaches/Treasure Coast/SW Florida
Counties Included: Palm Beach, Martin, St. Lucie, Indian River, Okeechobee, Lec, Hendry, Glades, Charlotte, Collier

PATIENT TALK

**So Long Mr. Terror
By Isaac Piperno**

Is it possible to get over the Terror of having ALS? I'm beginning to think so. When first told I had it, I was too stunned to really see what lay up ahead for me. Now after having it for a year and a half, I find Mr. Terror is loosing some of his steam. This doesn't mean I'm not scared anymore because there are days and there are days. This past year has been and continues to be a learning experience for me. When you meet your cohorts especially those who are much further along the disease trail than I am. I am still thinking about life and how good it is. When you see folks who can barely speak, breathe or move who are still fighting to stay alive. More than that how they encourage others to keep moving on and keep it going. This tells me there is something in our human spirit that is there and will be there to protect us from Mr. Terror. I'm beginning to feel it in myself even though I know my own condition is heading south. It has to be what GOD put into all of us to be used when tragedy strikes. So far all the people in the world, realize this spirit exists and will be there for YOU.



CAREGIVER'S CORNER

How to prepare for Vacation

During the summer, or at any other time of the year that you plan to travel or to vacation with a person with ALS disease, it is very important to examine the pros and cons of what may be ahead on the trip.



Vacations DO provide a sense of normalcy, continuity and brief memorable times together for many families.

Vacations are stimulating and often provide a supportive environment of friends and other relatives for an isolated caregiver. But, this requires planning, risk-taking, energy and back-up all the way.

Realistically evaluate the diagnosed person's wishes, and the skills he/she retains as well as the skills he/she has lost. Compare this evaluation with your wishes. Anticipate potentially stressful situations and design contingency plans to avoid them.

The preplanning is very important. Make a checklist of items to pack including food, medications, medical records, and wheelchair for long walks. To make reservations in the airline and hotel let them know if:

- You need assistance boarding the plane or bus. Request wheel chair (departure & arrivals). Try and reserve aisle seats.
- You require a rental car with hand controls.
- You need a wheelchair lift.
- How much you and your wheel chair weigh.
- You need a handicapped room.
- Ask if you need space in the room to accommodate the Hoyer lift.

- You need a raised toilet seat
- You need grab bars beside the toilet and/or the shower



Today's newest cruise ships accommodate wheelchair passengers as well, but they are very limited. Some may have 15 handicapped rooms. All ships have elevators. You can also reserve a wheelchair on board; I was on a cruise 2 months ago and I wheeled my husband all over town (St. Thomas-St Croix).

Tips

- Discuss your plans for traveling with your family doctor he/she can give you some recommendations to avoid unnecessary problems.
- Be sure and bring your insurance medical card and also Living Will.
- Stop frequently, every 2 hours and drink plenty of liquids while traveling
- Get an extra prescription for your medications, it could be obtained in any pharmacy
- Hold your mail at the post office

Keep the diagnosed person's diet and dining times simple and consistent. Be sure they are adequately protected from the sun and extreme temperatures. Offer fluids and snacks constantly.



Richard and Mary Rosen. The Venetian Hotel in Las Vegas, May 2000

During a hurricane watch:

- Stay aware. Listen to radio or television hurricane reports. Persons assigned to Special Needs Evacuation Centers should listen to the media and determine if they must evacuate and what time the centers will open.

**Rumor Control Lines
(IN DISASTER SITUATIONS ONLY):**

- Team Metro Hotline: 305 375-5656
- Haitian Support, Inc: 800-443-2951

- Broward County: 954 831-4000**
- Monroe County: 800-955-5504
- Palm Beach County: 407 233-3500

- Check your emergency supplies, turn your refrigerator and freezer to the coldest setting and open them only if necessary. Store drinking water in clean bathtubs and bottles.

- You should lock and board up windows, stow away small objects that could cause damage in high winds, remove outside antennas, and if you are going to ride the storm out elsewhere, turn the utilities off.



(Provides general human services assistance, community information and disaster information in Creole).

State of FLA Emergency Information Line: 800-342-3557

TTY: 800 226 4329

City of N. Miami Bch: 305 919 0892

City of Miami: 305 579-1800

City of Miami-Beach: 305 673-7222

During a hurricane warning:

- Listen to your radio or television for official instructions.
- Stay inside the house away from windows and glass doors. Secure windows and shutters
- If you've been ordered to evacuate, leave as soon as possible. Make sure you tell someone where you are going.

Emergency Evacuation Assistance Program

(People requiring assistance with daily activities, people with disabilities or with medical equipment that is electrically dependent should register as soon as possible)

- Miami-Dade County: 305 513-7700
- TDD: 305 468-5402
- Broward County: 954 357 6402
- Monroe County: 305-292-4591
- Palm Beach County: 407 233-3500
- Deaf Services TDD: 305 668 3323

Emergency Management Offices:

- Miami-Dade County Office of Emergency Management: 305 468-5400
- TDD: 305 468-5402
- Broward County Emergency Management: 954 831-3900
- Monroe County Emergency Management: 305 289-6018
- Palm Beach County Emergency Management: 305 289-6018
- American Red Cross Dade and Monroe County: 305-644-1200
- Broward: 954-763-9900
- Monroe County (Upper Keys): 305-852-9612
- (Lower Keys): 305-296-4033
- Palm Beach: 561-833-7711

ALS Delegation Meets With Congress During National ALS Advocacy Day

Delegates attended historic Senate Subcommittee Hearing on ALS

A delegation from South Florida joined more than 350 other ALS advocates in Washington, D.C. May 18 to meet with the leadership of the United States Congress to discuss support for The ALS Treatment and Assistance Act, the ALS - specific legislation introduced in both the House and Senate. In addition, the delegation attended the first-ever ALS - specific hearing before the Senate Appropriations Subcommittee of the Labor and Health and Human Services Committee, shared by Senator Arlen Specter, of Pennsylvania.

The group of South Floridians met with a representative from the offices of Senator Bob Graham and Senator Connie Mack to seek their support for the legislation, HR 353 and S 1074, which would

provide Medicare coverage for outpatient drugs and waive the 24-month waiting period for Medicare eligibility for ALS patients. The group also met with Congresswoman Ileana Ros-Lehtinen, who was the only one of the three Floridians to sign onto the bill as a result of the delegation's visit. Senators Frank Lautenberg of New Jersey and Paul Sarbanes of Maryland also signed on after visiting with Dr. Walter Bradley and two others members of the South Florida group.

At the conclusion of the day, the advocates joined members of Congress at a reception held in the United States Capitol. Attending the reception were Steve Beuerlein, quarterback



Dr. Walter Bradley, Magda Leuchter, Lisa Treister, Gail Scarpitta, Congresswoman Ileana RosLehtinen, Lisa Bell and Carol Gunter

for the NFL Carolina Panthers; baseball legend Steve Garvey; and Don Casey, veteran NBA coach.

Congresswoman Lois Capps of California receive the Jacob K. Javits Public Service Award, presented in memory of Senator Javits, who died of ALS in 1986. The award was presented to Congresswoman Capps for her invaluable efforts in support of finding a cure for ALS, and for her commitment to increasing the quality of life for those affected by the disease.

SAFETY CORNER

Hurricane Season

Hurricane season is from June 1 to November 30. Information on what to do if a hurricane is headed your way and a disaster plan will be explain as follow

Before a hurricane comes knocking:

- ALS patients on ventilators or dependent on electric equipment should refer to the "Hurricane Preparedness Tips" article that appeared in the Volume I, Issue 1 of our Miami-ALS Newsletter.

- Check your insurance. If you live in an area that could be affected by a hurricane's storm surge, make sure you have flood insurance.

- Prepare and take a box with your medical insurance papers, home owner insurance papers, valuable papers, etc.

- Plan a meeting place. Make sure that everyone in your family knows where to meet, a relative's house for example- to prevent family members from becoming separated.

- Pick an emergency contact.

- Develop an emergency communication plan in case family members are separated one from one another. Ask an out of state relative or friend to serve as the family contact. Make sure everyone in the family knows how to reach the contact person.

- Be ready to evacuate. When an order comes to evacuate your area, be ready for it. Have your car gassed up and your disaster kit ready to go.

- Emergency Evacuation Assistance Program (EEAP)

Many of your neighbors may need assistance with their daily living, and a disaster occurring makes them even more vulnerable. OEM maintains a registry of Miami-Dade residents that will need assistance evacuating before or after a disaster.

IT IS NOT JUST FOR HURRICANES! Any sudden incident that may require evacuations could trigger the need to help some of these residents with special needs.

Special Needs Evacuation Centers (SNECS) are opened as places of safety for residents on the registry. Registrants are provided with transportation when eligible, additional medical personnel at the SNEC, and placement at safe facilities until the threat from the disaster is over.

Anyone needing assistance with their daily living including having electrically dependent medical equipment, should register for the EEAP as soon as possible. Contact us by e-mail or call directly at 305 273-6790 - TDD 305 273-6711 to receive an application.

Providing free air transportation to distant medical care

To take part of one of the studies for ALS or to be under specific treatment in a place far from your town, sometimes is very difficult because you are unable to afford commercial airfare.

The good news is that there is an organization that can make a world of difference by providing free air transportation in a very caring, personal and stress-free environment. AirLifeLine is a national, charitable organization of private pilots that offers this service to people in financial need who have been touched by cancer or other illnesses.



Is it too good to be true? Definitely not and here's why:

For 22 years, AirLifeLine has called upon its network of volunteer private pilots across the country to donate their planes, flying skills and time to help others in need of a viable means of transportation to critical medical care. Because of the contributions of these pilots, AirLifeLine can offer this unique program at no cost.

AirLifeLine and its dedicated pilots can help you, a family member or someone you know who lives a long distance from his or her hospital, doctor or treatment center. The qualifications are few. Passengers should be:

- Traveling to and from medical treatment within approximately 1,000 miles from home.
- Medically stable to fly in a small, unpressurized single or twin-engine airplane.
- Mobile enough to board and exit the airplane.
- Unable to afford commercial airfare or use other transportation (call AirLifeLine for qualifications).

Each AirLifeLine round-trip flight is individualized to the passenger's needs. Your pilot will pick you up at the airport closest to your home and land at the airport closest to your medical destination. If you would like or need to bring a support person, you are encouraged to do so. AirLifeLine offers its services to people of any age and any illness.

For more information or to request assistance, call AirLifeLine toll free at 1-877-AIRLIFE (247-5433) from 7:30 a.m. - 4:30 p.m., PT, Monday-Friday, or visit Website www.airlifeline.org



RESEARCH CORNER

HAS YOUR PHYSICIAN ENROLLED YOU IN THE ALS PATIENT CARE DATABASE?

The purpose of the ALS Patient Care Database is to improve outcomes of persons with ALS. The database is one component of the ALS C.A.R.E. Program which is designed to improve the management of patients and to identify the needs of caregivers. Dr. Walter Bradley is a founding member of the Advisory Board of ALS Care, the database project gathers large amounts of clinical data that should help provide answers to several questions regarding ALS, including risk factors, diagnostic methods, functional status, quality of life, treatment strategies and management of ALS symptoms. The database will be a valuable tool for improving patient care and research. Quarterly reports of the data are issued to

physicians and newsletters are sent to patients. The Data Coordinating Center in the Center for Outcomes Research in the University of Massachusetts is responsible for analyzing the data, protecting confidentiality and promoting publication of database information. Contact your center or neurologist if you want to participate in this program.

PAST EVENTS

EVENING FOR HOPE

Pedro Gonzalez, owner of Fantasy Show Restaurant and Nightclub located at 3600 S.W. 8th Street, who also suffers of ALS, has decided to dedicate one day a year to ALS for the purpose of raising funds to benefit our ALS program.

On May 19, 2000, a gala was held at his Fantasy club with very good success, Mr. Gonzalez was honored with a plaque presented to him by Dr. Walter G. Bradley. Jose Perez Sr. was also acknowledged for his never-ending services to the University of Miami ALS program

The event attracted many stars in the Latin community, many of whom have dedicated their time to this cause before: Chayanne, Angela Carrasco, Sofia Vergara, Danny Daniel, Julio Sabala, Mauricio Zeilic, Betty Pino, Carolina Cristancho, Victoria, Marc Mejia, Alfonso Pahino and Cristian Show from Spain, Tomas Muñoz from Sony Music and Manolo Diaz from Universal Music Latin America. We were also graced by the presence of members of Ilva's family, D'Aldo, her spouse and her son D'Aldo Jr.

There was plenty of food, wine, rum and nostalgia to go around. But the night reached a peak when **Chayanne** appeared on stage; his emotion and sincerity surpassed anything imaginable,

and the everlasting search for the meaning of life, was center stage, where it belongs. Chayanne expressed his deep compassion for all the ALS patients, and his profound appreciation for friends and family of Ilva joining hands to keep her memory alive by helping others with ALS.

We are forever grateful to our **Volunteers, Event Committee and**

Friends of Ilva Romano, specially Rose McVeigh, Thalia Puente, and Adriana Gomez. Many, many **thanks** to all of them.

Where would we be without our **Sponsors!** We wish to thank them for their generosity and great support toward this event. The Sponsors that participated

are: Mr. & Mrs. N.C. Murthy, Fantasy Show, Esther Percal and Adriana Gomez, Universal Music Latin America, Sony Music, Jet Graphics, Univision, Lumari, eritmo, Ericsson, Southern Wine and Spirit of America, Brugal & Co. Inc, Simauchi Printing, Aventis Pharmaceuticals Inc. Thanks! Without you, we could never have come so far.



Cristian & Chayanne



Danny Daniel - Singer



Victoria - Singer



Pedro Gonzalez owner of Fantasy Show (1st Row)
Betty Pino (2nd Row)
Walter Bradley DM, FRC. P. (right)
D'Aldo Romano (left)



Alfonso Pabino - Sofia Vergara



Angela Carrasco and Rosa Silveira



Julio Sabala, Maribel Rodriguez from Sabado Gigante, Pablo Gonzalez owner of Fantasy Show



Jose Perz Jr., Elena Botero, Ginna Gonzalez y Graciela Reyes



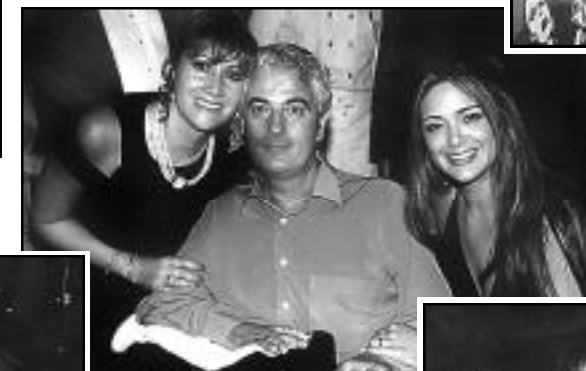
Mark Mejia - Singer



Dr. Verma, Jose Perez and Eusebia



Thalia Puente and Rose McVeigh



Ginna Gonzalez, Pedro Gonzalez and Jessica Fox



Frank Duran, Gloria Duran and Rosa Duran



Rosa Silveira and Bruce Pockman



Erick Fernandez, Chayanne, D'Aldo Romano y Tomas Muñoz