

The Kessenich Family MDA ALS Center

Please greet our new staff in the Kessenich Family MDA ALS Center and Multiple Disciplinary Team:

Graciela M. Reyes, RN, CGRN



Graciela is a nurse with 5 years of experience in nursing care and patient assessments in disciplines such as Gastroenterology and Neurology. She specializes in home health care

and patient education which will enhance our patient care and clinical coordination programs. In her spare time, she volunteers at the Catholic Hospice of Miami.

Kathy Parry, PT PhD

Dr. Parry is a physical therapist advising Center patients and their families in the



selection of assistive devices, orthopedic appliances, and home care programs. She started her career in public health and obtained vast general clinical experience as a consultant for the

Arthritis Foundation and for Joslin Diabetes Center, Baptist Hospital.

Joey Speaker, RD, CNSD

Joey is a clinical dietitian providing clinical nutrition services to Center patients. She has provided nutritional assessments, implementation, and monitoring of intensive care patients in many of



the local hospitals and medical centers in the Miami area for the past 7 years. Joey instructs patients and their families in nutritional awareness, healthy habits, and weight loss prevention.

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Doctor's Corner

Model animals in ALS research Ashok Verma, MD



Approximately 10% of human ALS (Lou Gehrig's disease) is familial, i.e., the disease is inherited through defective genes. Because there are more similarities

than differences in genetic make-ups of humans and other mammals, it is not surprising that ALS-like motor neuron diseases (MND) also occur in animals. At least four different forms of MNDs have been recognized in mice. One equine form of sporadic MND has also been recently reported. In addition, using modern molecular genetic techniques, it is now possible to insert faulty human ALS genes into the genetic pool of animals and thus create a human counterpart of human ALS in animals.

There are two major reasons why animal models are needed for the advancement of ALS research. The first is a purely practical one: these animals are needed for screening of the therapeutic agents. As the basic research in ALS progresses, new drugs that have rational bases for use in ALS will be developed, and for their screening, the

need for appropriate animal models will grow. The second reason why animal models are needed is that these models can be used to study the mechanism of disease. Animal models improve our understanding regarding the cause of ALS and why the nerve cells fail to function and die in ALS.

What do we require from an animal model of ALS? First, it obviously should resemble the disease pattern found in human ALS. In strict sense, this requirement appears insurmountable because the motor nervous system in humans is more complex (than in animals) and certain of its components are nonexistent or are only primitively developed in lower animals. Nonetheless, involvement of homologous parts of the nervous system in animals should fulfill the criteria for a successful model of human ALS. Second, the structural changes in nervous system should resemble those found in human ALS. Again, a perfect replica of ALS currently does not exist, mainly because human motor architecture in the brain is somewhat different than that in animals, but the findings in several models show many morphological abnormalities of the human counterpart. Third, the model animal should be relatively small and reproducible and should be easy to handle. The mouse or other small animals fit this example better than the larger animals, such as primates.

Currently available animal models of MND fall into three broad categories: familial (hereditary), sporadic (isolated), and experimentally induced (transgenic). Several murine models of MND occur in nature. The Wobbler mouse is one of the better studied naturally occurring models of MND. As the name indicates, these mice become progressively weak in later age and they begin to wobble. An interesting sporadic (nonfamilial) MND has been discovered

in horses in the northeastern United States. As expected, similar to Wobbler mouse, this equine form of MND also lacks spasticity, presumably due to rudimentary motor nerve fibers that travel from the brain to the spinal cord in these animals. The cause of equine MND is currently unclear. Experimentally induced (transgenic) models have been recently constructed by inserting copies of defective human ALS genes, such as SOD1 and neurofilament genes, into the animal's genetic pool. Particularly in human-SOD1 mouse model, a progressive weakness and atrophy of muscles develop in a relatively fixed time frame. The course of SOD1-related disease is generally short and is analogous to human ALS. In these models, the activity of the natural mouse gene is normal. This observation, in combination with the finding that high expression of the normal mouse gene neither induces nor protects the damage by the faulty gene, indicates that the defective SOD1 gene in familial ALS causes some deleterious gain of function. The nature of this genetic toxic gain of function and why it selectively attacks certain brain and spinal cord cells are the subjects of intense current research.

Transgenic mice expressing defective human ALS genes have been used to document the modest beneficial effect of certain therapeutic agents, such as riluzole and vitamin E. Further studies will be aided by identification of other genes linked to familial ALS. Over the coming years, these model animals will help investigate the ways in which defective genes damage nerve cells, the steps of biochemical pathway that eventually results in nerve cell demise, and the treatments to target these detrimental steps to arrest and reverse the ALS disease process.

Patient Corner

Tips

- 1) A good gel or dense foam cushion for the wheel-chair is always needed for adequate trunk and pelvic support.
- 2) For a "drop foot" (frequent falls)

you need a ankle foot orthoses AFOs.

- 3) Electric beds facilitate safe standing and sitting and maintain independence.
- 4) Hydraulic lift is used for lifting in and out of bed, wheelchair, commode, etc., (Hoyer lift).
- 5) If you have neck and shoulder weakness, you should use a cervical collar. Ask your doctor or nurse to prescribe the best for you.
- 6) If you have upper extremity weakness, you can use utensils holders, extra long straws, lightweight large handle cups, plate guards. Mobile Arm Supports (MAS) allow horizontal/vertical motion self feeding and personal care.
- 7) If you are taking Rilutek (Riluzole) do not forget to have a liver enzyme test every 3 months.
- 8) If a PEG will be used, it should be started early before you start with respiratory problems and it does not need to be used initially except as a supplement to oral intake. Waiting too long may increase the risk of complications if respiratory muscle weakness is progressing.
- 9) A chin strap is helpful to keep the mouth closed and avoid dryness of the mouth.
- 10) A head strap is helpful also to keep your head in upright position. If you are in the car attach it to the head rest of the chair.
- 11) If you use any respiratory device, it is very important to regularly check the setting of the equipment to be sure they are correct, as respiratory muscle weakness progress.
- 12) If you have respiratory muscle weakness talk to your doctor about the BiPAP (bi-level intermittent positive pressure), which is a non-invasive ventilator that reduces the work of breathing and improves not only gas exchange, but also exercise tolerance and sleep quality.
- 13) If you can not clear airway secretions by yourself because of respiratory muscle weakness, talk to your doctor about the use of a mechanical cough machine called "InExsufflator" made by Emerson.
- 14) If your PEG is out of place, call

your doctor and go to the emergency room as soon as possible, the hole will close in 24 hours.

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Veterans must first be enrolled to receive care

To receive healthcare under the new program, veterans must first be enrolled

Veterans can obtain application forms for enrollment by visiting, calling, or writing to their nearest VA healthcare facility or veterans benefits office. Completed applications may be submitted in person or by mail. Web site: <http://www.va.gov/health/elig> Enrollment means veterans are eligible for a comprehensive healthcare benefits package of inpatient and outpatient services. Among these services are the following:

- Preventive services, including immunizations, screening tests, and health education and training classes.
- Primary medical care, including outpatient surgery.
- Diagnosis and treatment
- Surgery
- Mental Health and Substance Abuse Treatment.
- Home healthcare
- Respite and Hospice Care
- Emergency care in VA facilities.
- Drugs and Pharmaceutical.

If for any reason a selected facility is unable to provide the healthcare needed by enrolled veteran, the facility must make arrangements for that care to be provided by another VA facility or by one of VA's private sector contract affiliates.

Why should I enroll?

You should enroll to ensure that you may receive the comprehensive benefits package offered through VA's national healthcare system. In addition, your enrollment will help VA plan its delivery of quality care.

I'm already receiving VA healthcare service. Do I have to apply for enrollment?

If you have been receiving VA healthcare services since October 1, 1996 you do not need to apply. In this case, VA will

process an application on your behalf.

Should I give up my existing healthcare coverage if I enroll with the VA?

No, you aren't required to and we don't encourage it. VA healthcare is dependent on the level of Congressional appropriations, not on premiums paid by enrolled veterans. Veterans with private insurance or other public coverage such as DoD, Medicare, or Medicaid may find VA enrollment to be a complement to their coverage.

My Book of Recipes



Dietary Specialties

PASTA PURÉE™ PREPARATION

Ingredients:

- Water 1/2 c.
- Salt(optional) pinch
- PASTA PUREE™ 3 tsp.
- Instantized pasta
- THICK & EASY® 1 tsp.
- Instant Food Thickener 1 tsp.
- Butter or Margarine 1 tsp.

Serves 1 (1 1/3 Tbsp. Dry)

DIRECTIONS

1. Bring water and salt (if desired) to a boil.
2. Whisk in THICK & EASY® Food Thickener and PASTA PURÉE™ Instantized Pasta,
3. Whisk in butter or margarine.
4. Cover and place on a steam table for 30-45 minutes.
5. Whisk again before serving.
6. PASTA PURÉE™ Instantized Pasta

can be scooped directly onto the plate and topped with a thick sauce. If desired, place in pastry bag and shape into spaghetti, noodles, or other pasta shapes; or place in forming molds for ravioli.

Cooking Tips

PASTA PURÉE™ Instantized Pasta achieves its best consistency and will be easier to shape if allowed to sit for 45 minutes after cooking. Prepared PASTA PURÉE™ Instantized Pasta freezes well; just reheat and serve.

Customer Tips

Substitute flavored broth for water. This will increase sodium, however.

** When prepared as directed, mar - garine, salt, and THICK & EASY® Instant Food Thickener contribute an additional 44 calories, 3g Total Fat, 210 mg Sodium and 4g Carbohydrate per serving.*

*** Percent Daily Values are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.*

CHOCOLATE - BANANA PUDDING

- One 8 oz. can Vanilla ENSURE PLUS
- 2 Teaspoons unsweetened cocoa
- 2 Teaspoons sugar
- 1 Small, ripe banana
- 1/2 Teaspoon cinnamon
- 5 Tablespoons DIAFOODS THICK-IT

Per serving

Sodium, mg	151
Potassium, mg	496

Patient talk



Darryl Strawser, who has had ALS for what his specialist estimates to be 10 years, was first diagnosed in 1996 at the age of 32. His physician, Dr. Walter Bradley, has studied

this case closely because of Darryl's unique situation of having the disease for such an extended period of time, at such a young age, and being determined to live an active and productive life.

Darryl is a photographer by profession. His artistic eye and human compassion has spanned a broad range: journalistic, covering events such as the Equal Rights March in Washington DC in 1993 - covering The White House in 1989 and 1990 - albums covers for musicians such as Nestor Torres - Fashion and Commercial Imagery - and Fine Arts works that hang in private collections. They have been published in books, and been the genesis of a line of greetings cards. But, as many know - an artists life is not necessarily financially rewarding. But artists don't pursue their careers for monetary rewards - it is usually based on a passion and a vision that they are driven to share with others.

As Mr. Strawser's life is affected by ALS, the physical demands offer him the opportunity to make small changes in his passions. Presently, been less able to shoot, he has embarked on the monumental task of categorizing his own image library and creating a stock image company of his own works while also representing other talented artists - offering these artists the opportunity to showcase their works, sell their works, and live a legacy sculpted by their own visions.

Which brings up an opportunity for assistance and donations to Mr. Strawser's art and career. As we are all aware, sometimes we have to ask for help to realize our ambitions. Mr. Strawser is in need of the proper computer equipment to facilitate this next phase of his passion. High-memory, fast processor CPU, digital storage equipment, and high resolution scanner are among some of his needs. If you or anyone you know may be of financial assistance or can donate equipment for the next phase of Mr. Strawser's visual legacy, you may contact:

Ginna Gonzalez, Phone: 305-243-7400



Caregiver's Corner

Think Positive

Inspiration from one of America's greatest motivators
By Norman Vincent Peale

If you want to get somewhere, you have to know where you want to go and how to get there.
Then never, never, give up.

The secret of life isn't in what happens to you, but what you do with what happens to you.

Help other people to cope with their problems and your own will be easier to cope with.

Never use the word *impossible* seriously again. Toss it into the verbal wastebucket.

Self-trust is the first secret of success. So believe in and trust yourself.

Stand up to your obstacles and do something

about them. You will find that they haven't half the strength you think they have.

Joy increases as you give it, and diminishes as you try to keep it for yourself. In giving it, you will accumulate a deposit of joy greater than you ever believed possible.

How you think about a problem is more important than the problem itself-so always think positively.

Go at life with abandon; give it all you've got. And life will give all it has to you.

ALTERNATIVE COMPARISON LIST

ALTERNATIVE

DESCRIPTION

COSTS

Home Health Care

Home Health can provide a wide range of services, from companions to full 24 hour care. An evaluation of the client will be performed by a Registered Nurse that works for the agency, and the services will be matched with the needs of the client.

Services may be covered by Medicare, Medicaid or a Long Term Care Insurance policy. Physician must authorize services being provided for Medicare coverage.

Note *Homemaker services are not covered by Medicare*

Retirement Community (Independent Living)

RENTAL: Designed for individuals who are relatively independent, physically and socially. Generally mid-sized to large campus-style communities that offer a wide variety of activities and conveniences for the resident. Generally meals, linen service and transportation are provided for the monthly rental.

RENTAL: Price ranges vary by type of community and size of apartment desired. Generally, most communities are private pay with no governmental financial assistance.

CCRC/LIFE CARE: Large, self-contained, campus-style communities that offer Retirement, Assisted Living and Nursing Services. Generally an initial entry fee and monthly payments guarantee the resident access to all specified health care services for the remainder of the resident's life.

CCRC/LIFECARE: Require an entry fee plus monthly payments with the arrangement to care for the resident for the remainder of his/her life. Most communities offer several contract options. Depending on the contract, the entrance fee may be non-refundable, refundable on a declining basis over time, partially refundable or fully refundable. Some communities offer full equity of purchase instead of an entry fee.

FEE SIMPLE-DEEDED OWNERSHIP Communities where you purchase you condominium/villa while offering the usual Retirement community services. Ownership communities DO NOT require a health assessment by a physician. Healthcare is paid for if and when needed.

FEE SIMPLE-DEEDED OWNERSHIP Capital Investment requires (purchase condominium/villa) equity ownership, 100% return on appreciation (earnings on sale)

Assisted Living Facility (ALF)

ALF's range in size from small homes housing 6 people to large full-service facilities. The range of services vary from facility to facility. Services typically include assistance with meals, bathing, dressings, continence care and other routine daily needs. Medical services vary by facility.

Price ranges vary by facility, depending on level of care. Charges are billed on a monthly basis. For lower income elderly some financial assistance is available through the Optional State Supplement Program, Medicaid Waiver or through the Veteran Administration as long as skilled care is not required.

Nursing Center

Skilled nursing care 24 hours a day. Physical and mental rehabilitation services available. Assistance with eating, bathing, grooming and continence care. Registered Nurses, LPN's and certified nurses aides on staff to provide care and dispense medications, resident must need 24-hour skilled nursing care and/or rehabilitative services.

Costs are figured on a daily basis and billed monthly. Medicare and Medicaid can assist in deferring high cost, however, a person must qualify by meeting both the physical and financial requirements.

Research Corner

Neuromuscular Studies Division

The Neuromuscular Studies Division at the University of Miami has been very busy with the lengthy Sanofi Study. The Study had two groups, the first group will finish August 1999 and the second January 2000. The results from the data collected will not be available until later in the year 2000. We would like to thank all those patients and their caregivers for their participation in the study.

We are planning to start two new study programs, both are 12-month studies, one study will involve an injection of a nerve growth factor, the second study will use an oral medication. We will start screening patients for both studies by the end of the August. If you are not sure if you are on the waiting list and wish to be added send the following information to: (Please note that you must be referred to the list by a University of Miami Neurologist, call (305) 243-7516 to schedule an appointment, if you have never been seen at the University of Miami)

University of Miami
Julie Steele, LPN, CCRC
1150 N.W. 14 Street, #701
Miami, FL 33136
Fax (305) 243-9412

Patient Information

Date

Date of Diagnosis

Address

List of Current Medications

Phone

Date of Birth

Familial ALS: Old and New Genetic Studies

Lisa Baumbach, Ph.D.,
Associate Professor of Pediatrics and Neurology,
University of Miami School of Medicine

Amyotropic lateral sclerosis

(ALS) is a rapidly progressive neurodegenerative disorder of motor neurons in the cortex, brainstem, and spinal cord; affected individuals usually survive for only 2-5 years after onset. The loss of motor neurons results in the wide range of signs and symptoms that comprise ALS, including progressive atrophy of skeletal muscles, fasciculations, spasticity and weakness. An autosomal dominant mode of inheritance is seen in approximately 10% of ALS cases. Family cases (FALS) can not be distinguished phenotypically from sporadic cases and provide a unique opportunity to study the cause of ALS using a genetic approach.

The objective of any familial ALS study is to screen the SOD-1 gene and identify mutations in FALS patients and their family members. This is accomplished by taken blood samples from family members. DNA is isolated from the blood, and use in various experiments to try to detect a possible mutation. Since 1992, the University of Miami Neurology Department in conjunction with Dr. Lisa Baumbach in Genetics have been identifying ALS families, collecting blood samples and examining the SOD-1 gene.

Recently, Dr. Lisa Baumbach and Dr. Robert Brown at Massachusetts General Hospital have received a three year grant from the ALS Association to find new genes which cause ALS. These studies will be using current methods used in the Human Genome project to scan the entire human genome for new ALS genes. If your family has ALS, please contact Dr. Lisa Baumbach at telephone: 305-2433-997 to enroll in this very important study.
(e-mail: lbaumbach@mednet.med.miami.edu)

Safety Corner

Why Are We Concerned About Year 2000(Y2K)?

Many computers, software and computer-driven products will exhibit some problems in working through the

transition into the next millennium. The digits were limited to six (DD/MM/YY), and no date beyond 19YY would be recognized. Most early microprocessor and operating system combinations did not have the capacity to compute the eight digits necessary to transition from the year 1999 to 2000. If left unaddressed, this could result in a system failure or miscalculations causing disruptions of operations including among other things, a temporary inability to process transactions or engage in similar normal business activities.

Mallinckrodt has developed and has implemented a comprehensive program to address the Year 2000 issue. The program has four major focus areas: information technology systems, products, and key supplier and business partners. Overall, the Company has, as of March 31, 1999, its targeted completion date, completed assessment in the above described areas, and has substantially completed required modifications, replacements or conversions.

Year 2000 compliance for these systems includes modification and testing of existing systems and replacement of certain systems with new technologies. Required modifications and replacements and testing thereof are substantially complete.

Year 2000 Product Compliance Detail

LP10 ventilator with serial number 111806 or higher are compliant. Systems with serial number 111805 or below are not Y2K compliant unless a Y2K upgrade has been installed by Mallinckrodt or a certified dealer

LP10-I ventilators with serial number 191504 or higher are compliant. Systems with serial number 191503 or below are not Y2K compliant unless a Y2K upgrade has been installed by Mallinckrodt or a certified dealer.

Determining Compliance Status

a) Find ventilator serial number and compare to serial number listed in Compliance paragraph above; or (b) Call Mallinckrodt Technical Support at 800-497-3787 with your serial number and



UNIVERSITY OF MIAMI
ALS RESEARCH
FOUNDATION



IMPORTANT

ILVA ROMANO MEMORIAL FUND PROGRAM

To be accepted by this program, you must meet certain eligibility requirements established by the Board of the University of Miami ALS Research Foundation.

Please review these carefully. Enclosed is an application, which must be returned by fax or mail as soon as possible.

- Patient must disclose personal financial information, including a copy of tax return information.
- Patient must provide documentation that all other avenues of funding have been exhausted.
- Patient must file for an Explanation of Benefit (EOB) with the insurance company.
- Patient needs to provide complete information about services or equipment for which he/she is applying, and their cost.
- Each separate request for assistance requires that a separate form be completed and submitted to the Foundation.

Unfortunately, funds are limited, thus there is no guarantee that funds will be available to assist all patients in their requests.

Please contact Ginna Gonzalez, R.N. with any question about this application:
(305) 243-7400 or (800) 690-ALS1, Fax: (305) 243-7525, e-mail: gina@waltek.net.

PATIENT SERVICE REQUEST

PATIENT

Name (last, first, middle) _____ Age _____ Sex _____

Home Address _____ Phone _____

City _____ State _____ Zip _____

Health Insurance _____

Responsible Family Member _____ Relationship _____

Address _____

City _____ State _____ Zip _____

Physician's Name _____ Date _____

Address _____ Phone _____

City _____ State _____ Zip _____

FINANCIAL INFORMATION

Monthly Income: Partner/Spouse \$ _____ Soc. Sec. \$ _____ Pension \$ _____

Other Assistance Contacted: _____

Please explain why health insurance is not a viable option for acquiring the services/equipment you required: _____

Service or equipment request (please type or print neatly, and provide justification for the need for services/equipment) _____

FOR OFFICE USE ONLY

Service Approved: Yes No
Total Amount: \$ _____
Authorized Signature: _____ Date _____ Phone _____

ask for status; or (c) verify that the calibrator displays or the printout shows "Y2K" after the model name.

Year 2000 Issue:

Noncompliant versions of the LP10/LP10-I Ventilator will properly transition to the year 2000 on January 1, 2000 but are not fully Y2K compliant because their system calendar does not recognize "leap" years: instead of advancing to February 29, during leap years, the date will advance to March 1. Printout will remain one day ahead until the next service, PM, or Re-certification.

The date is not used in internal calculations or ventilator functions, and will not affect the operation of the ventilator or any of its accessories. The date mismatch will only be noticed when the vent is connected to a printer. The effect can be minimized if the ventilator is serviced soon after February 29, and the vent date is corrected. A Y2K upgrade is available upon request.

Upgrade:

Beginning April 1, 1999 upgrades can be installed in non-compliant LP10/LP10-I ventilators by Mallinckrodt or certified dealers upon request. Mallinckrodt Technical Support can be reached at 800-497-3787

Charges:

There is no charge to upgrade in-warranty product during routine service. A charge of \$30 for Y2K upgrade will be added to routine service charges for systems not covered by warranty.

LP6+ ventilators with serial number 134936 or higher are Y2K compliant. Systems with serial number 134935 or below are not Y2K compliant unless a Y2K upgrade has been installed by Mallinckrodt or a certified dealer.

For Nelcor Puritan Bennett, Aequitron, EdenTec and Infrasonics Products

In the United States and Canada

Contact the Nellcor Puritan Bennett Technical Services Department

1-800-635-5267
(1-800-NELLCOR), press 3, or
+1-925-463-4000 ext. 6300
Fax: +1-925-463-4720
In Mexico and Central and South

America
Phone: 1-925-463 4000 ext. 6300
Fax: 1-925-463 4720
Website:
<http://www.Mallinckrodt.com/Corporate/Y2K/asp/index.asp>

Events

GOLF TOURNAMENT

February 26, 2000 • Golf Club of Miami
Contact person: Tod Roy
(305) 884-2352
or José Pérez: (305) 271-9502



	Cape Coral	WFTX	36	11:00 pm
	Gainesville	WCJB	20	9:00 pm
	Jacksonville	WAWS	30	8:00 am *
	Miami/Ft. Lauderdale	WBZL	39	10:30 pm
	Orlando/Daytona Beach	WOFL	35	9:00 pm
	Panama City	WMBB	13	8:00 pm
	Sarasota	WWSB	40	9:00 pm
	Tallahassee	WCTV	6	9:00 pm
	Tampa/St. Petersburg	WFTS	28	9:00 pm
	West Palm Beach			
				

Starts Sunday 9:00 p.m. on WPEC-TV, Ch. 12, then switches to WPXP, Ch. 67, Monday, at 11:00 a.m.

* Telethon starts morning of Sept. 6; current as of 7/19/99

Past Events

On May 20th PALS and family members from Florida went to Washington, D.C. to participate in the ALS Association's National Advocacy Day. We had the opportunity to meet with members of Congress to educate them about ALS and ask for their support on the legislation H.R. 353. that contains two separate components:

- 1) Waive the 24-month Social Security disability waiting period for ALS patients to receive Medicare and
- 2) Provide for Medicare coverage for all FDA approved drugs prescribed for use in the treatment of ALS. (for more information, please visit our web-site: www.miami-als.org It was a wonderful experience.



Mardi Gras Theme For Fund Raiser

On July 26, 1999, Geoff and Nancy Bailey hosted a fundraiser for the University of Miami ALS Foundation. The event was held at the BlackHawk Cafe in Fort Myers, Florida, where the couple reside. Since being diagnosed two years ago with ALS, Geoff and his wife Nancy, have dedicated their lives to helping find the cause and cure for this disease.

The party had a Mardi Gras Theme. The evening began with a preview of Geoff's award winning short film about ALS. Then, Mitch Schwenke, owner of the restaurant, was given an inscribed crystal vase for his hard work and dedication. He

was completely surprised. The presentation was followed by a speech given by Nancy Bailey. She opened with a quote from a letter the couple received from Dr. Walter Bradley wishing them luck with the fundraiser in hopes they would "be able to raise money for the ALS Research Program, for we art down this year and I am likely to have to stop our project on the mouse model of ALS". Nancy went on to explain the importance of this project. She closed by thanking all who attended and told them that when the cause and cure for this disease is found they wouldknow that they all had played an important part.

Before the festivities began, Mitch asked that no one forget the reason they were there.

Guests were treated to an awesome

Louisiana Cajun Buffett and an evening of dancing and fun featuring Zydeco Blues King "Chubby Carrier and the Bayou Swamp Band".

Nancy and Geoff's family, friends and co-workers in the film industry attended the event and made it a success. The event raised a net profit of a little more than \$ 4,000.

Because of local news coverage, there has been heightened awareness of ALS in the community. Geoff and Nancy have been approached by a few people who want to help with their fundraising efforts. They are now in the early planning stages for two more events.

The Mediterraneo Renaissance Fair of Lake Tahoe

The Mediterraneo Renaissance Fair of Lake Tahoe, California was held in honor of the University of Miami ALS Research Foundation on the weekend of June 18-20, 1999.



The third Annual Mediterraneo Renaissance Fair of Lake Tahoe, California was held in support of our basic research program into the cause of ALS. The president of The University of Miami ALS Research Foundation is José Pérez Sr.. The Renaissance Fair is the brainchild of Mrs. Christine Karnofsky and her friends in the Expression for Life Funding Foundation of Lake Tahoe. Her brother, Geoff Bailey of Naples, Florida has ALS, and the whole family is working as hard as possible to raise the funds needs to find the cause and cure of ALS.

The Renaissance Fair started with an Evening at the Casbah with a dinner and a show. Christine Karnofsky and her friends put on a great show of belly dancing and other forms of Arabian entertainment, The Fair covered a three acre site with booths and craft exhibits with a medieval theme. The exhibitors were in Elizabethan costumes and it was a very exciting event.



We at the Kessenich Center in the University of Miami ALS Research Foundation want to thank Christine Karnofsky, Geof Bailey and their friends for all their help in trying to achieve our goals,

Walter G. Bradley, DM, FRCP
Professor and Chairman

IMPORTANT NUMBERS

Kessenich Family MDA ALS Center	1-800-690-ALS1 www.miami-als.org
Muscular Dystrophy Association	1-800-289-0535 www.mdaua.org
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

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 for an application. This could be family members who have had experience with ALS patients and now have time to volunteer, or even health care professionals.



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The Kessenich Family
MDA ALS Center
1150 N.W. 14 Street
Suite 700
Miami, FL 33136

CALENDAR

SUPPORT GROUP

The ALS Support Group is held in the University of Miami Hospital and Clinics, 1475 N.W 12th Avenue at 12:00 - 1:30 p.m.

September 18, 1999

October 16, 1999

November 23, 1999

December 04, 1999

“THE Mc FARLANE COLLECTION”

Coming to Pro -Player Stadium September 3, 4, at 5:00 p.m. and September 5, at 2 p.m.

Contact person: Gold Coast Chapter

561-871-2453

Exhibition of Sammy Sosa's home run balls and Mark McGwire's home run balls.

“ The grand essentials to happiness in this life are something to do, something to love, and something to hope for”

Joseph Addison

EDUCATIONAL SYMPOSIUM IN SARASOTA

January 15, 2000

Contact person: Dr. Petrella

Phone: # 941-378-5153

HOLIDAYS CARDS AVAILABLE FOR SHIPMENT



SEPTEMBER 15, 1999

The card chosen is from a painting donated to the Kessenich Center by **Romero Britto**, the famous Brazilian artist who fills these small jewels with layers of color, bold lines, and patterns that bring each piece to life.

Twenty (20) cards \$ 17.00 plus postage and handling.

Each packet of cards includes brief information about ALS.

Please send check or money order to:
Kessenich Family MDA ALS Center
Holiday Cards
1150 N.W. 14th Street Suite 700
Miami, FL 33136



The picture is not an actual painting, this is a sample.

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