THE ALS
UNIVERSITY OF Miami
KESSENICH FAMILY MDA
ALS Center
NEWSLETTER

Volume 5 • Issue 4 • Winter 2004 The official newsletter of the University of Miami ALS Center

Kessenich Corner

Ginna Gonzalez was awarded the Vicky Appel MDA/ALS Distinguished Lecturer, 2004

Baylor Collage of Medicine,
Houston, Texas

Ginna Gonzalez, Director of Nursing of The Kessenich Family MDA ALS Center at the University of Miami, was honored as the Distinguished Lecturer for the 6th Annual Vicky Appel MDA/ ALS Patient Care Conference 2004. This honor is bestowed upon a nurse who has dedicated her life to make a difference in patient care. This conference, named in honor of Vicky Appel, celebrates a life long career dedicated to nursing education and the care of patients with neurological disease.

Ginna was born and raised in Bogotá, Colombia where she attended the Universidad Javeriana's Nursing School. In 1984 she moved to the United States and became a Registered Nurse. She began working at North Gables Hospital in Miami, Florida. During those years she worked in the Department of Internal Medicine, Telemetry and ICU. She later became Head Nurse of the Out- Patient Department. After having eight years of experience, in 1992 she took up the position of Director of Nursing for the Endoscopy Center in Miami, under the supervision of the National Corporation, AMSURG, and received the Commendation Award for Excellence from JCAHO in 1995, and became gastroenterology certified. In 1997, she accepted the position of Corporate Director of Nursing for the HMO Leon Medical Center. She moved to her current position of Director of Nursing of the Kessenich Family MDA ALS Center at the University of Miami in 1998, where she developed the multidisciplinary clinic, website, newsletter and support groups for the care of ALS patients.

Nurse Gonzalez has been a member of the National Neuromuscular Nursing Advisory Board since 1998. She was a successful member of the Association of Hispanic Nurses and the Society of Gastroenterology Nurses and Associates SGNA.

Nurse Gonzalez is married to Nestor Sanchez, a successful Industrial engineer with an MBA from the Florida International University. They live in Miami, Florida with their three children who are 17, 16, and 14 years old. Her hobbies include traveling, reading and enjoying the beach.

Past Vicky Appel Distinguished Lecturers include: Nailah Siddique, RN, MSN. (2003); Maura Del Bene, MS, RN, NPP (2002); Linda Boyton De Sepulveda, RN, CRNP, Ph.D. (2001); Lora L. Clawson, MSN, CRNP (2000) and Dee Holden Norris, RN, BSN (1999).

Ginna Gonzalez, RN and Dr. Stanley Appel

left to right: Maura Del Bene, RN, Nailah Siddique, RN, Laura Clawson, RN, Ginna Gonzalez, RN, Dr. Stanley Appel, Dee Holden Norris, RN and Linda Boyton De Sepulveda, RN.

Respiratory Management in ALS

By Ashok Verma, MD, DM
Co-Director
Kessenich Family MDA ALS Center

Progressive weakness of respiratory muscles and the consequent shortness of breath is a serious complication of ALS. The respiratory muscle weakness in patients with ALS can also result in decreased voice volume and inability to effectively cough and clear secretions, with the added risks of aspiration and pneumonia. Management of respiratory problems in patients with ALS often requires significant changes in daily life style and care plan. The respiratory interventions, including tr acheostomy and advanced life techniques, are among the most significant decisions that a patient with ALS and their families will face in dealing with the disease. Difficult as it may sound, the physicians and other care givers should always encourage patients with respiratory symptoms to initiate an open and honest dialogue regarding prognosis and treatment options.

Respiratory muscle weakness and sense of breathlessness

The breathing pattern is controlled by a series of central and peripheral mechanisms that can adjust the breathing appropriate by the body's demand. A normal resting person is unaware of the act of breathing. One may become conscious of breathing during unaccustomed physical exertion. However, in a normal person, this does not bring significant unpleasantness and it is generally accompanied by an assurance that the unpleasant sensation is transitory and will decline after exertion. Shortness of breath or dyspnea is an abnormally uncomfortable awareness of breathing. In ALS, shortness of breath is from respiratory muscle weakness that cannot be driven by central drive appropriate to the body's metabolic requirement.

Almost everyone with ALS will unfortunately face declining respiratory function as the weakness progresses. But the decline in respiratory muscle differs in different patients. Although isolated weakness of respiratory muscle can occur on occasion, respiratory weakness often parallels that in other adjacent muscles, such as neck muscles, arms and throat. Respiratory muscle weakness is generally early in bulbar ALS and late in leg-onset ALS. With the onset of respiratory muscle weakness, a patient with ALS may begin experiencing shortness of breath in activities as simple as walking up stairs.

However, many patients may not be aware of this limitation if the ALS has affected leg muscles, and thus is limiting their ability to walk.

In these circumstances, patients may experience breathlessness following physical therapy, or weakness of breathing muscles may be noticed in other ways, such as decrease in the power of voice, inability to complete long sentences during conversation, and reduced ability to cough and clear phlegm. Shortness of breath on lying down is particularly common with weakness of the diaphragm (the dome of muscle at the bottom of chest).

A weakened diaphragm can be gravity-pushed up by abdominal organs, when patient lays flat on the back, and the weak diaphragm may be unable to push down the abdominal organs during inhalation. This results in discomfort and a sense of suffocation on lying down flat on the back. Such patients may require several pillows or a wedge to prop them up during night-time sleep.

Diagnosis of respiratory muscle weakness.

The shortness of breath in the absence of heart and lung diseases is a clue to respiratory muscle weakness.

In ALS the diagnosis is straightforward. The clinical weakness of respiratory muscle is confirmed by pulmonary function testing. One simple test often performed is 'forced vital capacity'. Respiratory muscle weakness typically results in decrease in the amount of air that can be forcibly inhaled and exhaled. Unrelated lung diseases, such as emphysema or lung fibrosis, may complicate the interpretation of the test results in patients with ALS.

Other pulmonary tests include Maximal Inspiratory Pressure (MIP) or Maximal Expiratory Pressure (MEP) developed during forced inhalation and exhalation, respectively. Maximal Voluntary Ventilation (MVV) is yet another measure of weakness and fatigability of the respiratory muscles. Diseases with airway sensitivity, such as bronchial asthma, and other lung diseases may independently affect the MIP, MEP and MVV and one has to be careful in interpreting test results in the presence of a concurrent lung disease.

Performance of the above tests requires that the patient be able to blow into the testing machine with a good lip-seal around the mouthpiece. This may be difficult in bulbar ALS with lip and face muscle weakness and the test may show a falsely low measurement. Patients with a predominantly spastic form of ALS may not be able to voluntarily recruit respiratory muscle and thus may also show a low test result.

(Cont. from page 2)

Measurement of arterial blood gas is another useful test. It can be done from a blood sample collected from an artery at wrist. Overnight pulse oxymetry is another (noninvasive) way to determine the body oxygenation status. Compromised breathing from muscle weakness often decreases the amount of oxygen in blood and increases the amount of carbon dioxide (normal waste product that needs to be cleared by lungs).

Management of respiratory weakness in ALS

ALS is a progressive disease; the decline in respiratory muscle strength tends to continue to progress. Serial measurements and monitoring of respiratory muscle strength constitutes an important component of ALS clinical care. When the respiratory function falls below a basic level, the patient is generally unable to maintain adequate gas exchange and becomes symptomatic. Frequently, before this point is reached, patients with ALS can be at risk for rapid deterioration from aspiration due to mucous plugging or pneumonia. This deterioration can occur suddenly or over a period of hours or days even in patients who had been previously stable, albeit at low levels of respiratory function. Medical management can often clear the acute complication in such cases, but added compromise in respiratory function and interval progression of ALS may result in permanent dependency on assisted ventilation. For this reason alone, plans regarding options for respiratory support should be discussed and the patient and care giver be counseled at the beginning of the respiratory decline and certainly when the vital capacity declines to approximately 50 percent.

General measures such as adequate rest and optimal nutrition are important to optimize health and functionality in ALS. Difficulty with feeding in bulbar ALS needs particular attention as poor nutrition and aspiration and the associated complications can complicate existing respiratory compromise. A newly placed feeding tube may temporarily splint the diaphragm and decrease local chest movement and pulmonary gas exchange. Measures to prevent aspiration and pneumonia in susceptible individuals can not be overemphasized.

It is advisable for ALS patient to receive pneumonia vaccine and flu shot before the season. The patient and care giver must be trained to perform the Heimlich maneuver for an emergency situation.

Faced with the significantly weak respiratory muscles and continued respiratory decline, there are few treatment options. These must be individually discussed and considered with the patient and family within the context of quality of life and the realistic goals of treatment.

1. Assisted ventilation by noninvasive ventilatory support: Most patients opt for noninvasive ventilation when significant respiratory decline has been reached. The tabletop equipment is called BiPAP (bilevel positive airway pressure) machine. The patient is generally connected via a face mask or nasal pillow to the BiPAP machine. Noninvasive respiratory assistance is usually used intermittently, often at night, and it is very beneficial for respiratory symptom relief. BiPAP is not considered a life support device. However, BiPAP may not be adequate to provide complete ventilation in a patient with very poor muscle strength or with diminished control of face muscles (bulbar ALS).

2. Tracheostomy and direct ventilatory support. This is an invasive form of respiratory assistance. A tracheostomy hole is made in the neck and a tracheostomy tube is placed directly in the windpipe. It is connected to a ventilator and the system allows high-pressure machine ventilation that completely supports the breathing needs of the patient. Tracheostomy and permanent ventilation is a life support option. A number of issues, including the complexity of health care delivery, finances, quality of life of both patient and care giver, and the prolongation of a chronically progressive and debilitating disease process, need to be addressed before an informed decision is made by the patient or the healthcare surrogate.

3. No mechanical support: This option must be combined with symptom relief and palliation with medications and emotional support, realizing that failing or ineffective respiration will be fatal. Hospice services are important for patients requesting no mechanical support of terminal respiratory failure.

Conditions of Upper Limbs in the Patients with ALS

By Laura Guzman, MA, OTR-L

Lou Gehrig's Disease or Amyotrophic Lateral Sclerosis is caused by changes in upper and lower motor neurons which directly affect the soft tissue such as muscles, tendons and fascias. The soft tissue loses its properties such as resiliency, strength and length. Consequently, there is weakness, decreased movement and strength, stiffness and lack of coordination in the upper limbs.

To better understand the properties of the muscles and tendons and their direct relationship with movement, strength and coordination, let's explain each of them:

• Muscle Tone is the property of the muscle to stretch and contract smoothly during passive movement (another person actually moving the arm of the patient). There is "high" (hypertonicity) or "low" (hypotonicity) muscle tone. Hypertonicity which is also known as "spasticity" is detected when increased resistance is found during passive stretching of the limb. On the contrary, hypotonicity which is also known as "flaccidity" is present when there is no resistance found during passive stretching and limbs swing loosely.
• Strength is another property of the muscles and tendons which refers to the ability to contract actively against gravity considering the standards of specific age, sex and body constitution. Therefore, lack of strength will impede a person to raise the arm over head to reach an object from the kitchen cabinet.
• Endurance on the other hand refers to the ability of sustaining muscle activity for a period of time to accomplish a task. An example of this is when a person is able to reach over head with both arms to brush her hair; however she cannot complete the task due to the arms getting fatigued almost immediately.
• Coordination refers to the flow of movement, involving quality and speed of movement which can affect activity accuracy of gross as well as fine motor performance. This is most readily perceived during writing skills, involving grasping of a tool and controlling movements in order to produce a legible handwriting. When there is a malfunction of the soft tissue it definitely and directly alters the muscle properties discussed above.

We can see this in the various conditions of the upper limbs in patients suffering from ALS disease:

• "Frozen shoulder" which is severe restriction of movements found in the muscles and ligaments of the shoulder girdle, seriously limiting the passive and active movement of the shoulder.

• "Subluxation" of the shoulder in which decreased muscle tone or hypotonicity takes place in the muscles of the shoulder girdle results in the separation between the head of the humerus and the socket of the scapula. Muscles and tendons in this area are too weak and stretched to produce a movement of the arm.

• "Wrist Drop" is characterized by increased weakness or hypotonia of the extensor muscles of the wrist. They are no longer able to contract actively against gravity making it very difficult for the patient to reach and grasp objects.

• "Atrophy" of deep and small muscles of the hand prevents patients from opposing the thumb to the rest of the fingers to produce a pinching pattern, which is essential for picking up small objects such as pills, buttons and keys.

Even though therapy cannot improve or stop the progress of the various conditions caused by ALS. Intervention of various therapies, drugs, physical, occupational and speech, share the common goal of treating the condition by focusing on the remaining useful patterns of organization and adapting them to functional needs. We know that therapy can bring changes in the neural organization as to new pathways. However we are uncertain how this specifically works, so we as occupational therapists rather focus on discovering what is left and work with that in order to maintain it rather than bring back what is gone.

CONTACT: Diane Manning (305) 2618723

- FORD Club Wagon 1989
- For handicapped
- Seats 8ft
- Hand controls
- Low mileage
- Good condition
- $3,000.00

FOR SALE

Ford Econoline E-150 handicapped equipped Van. Excellent condition, immaculate condition. $25,000. Only 24,0000 miles. Many extra features, including:

Dual Captain chairs, front
High-top (extended roof) to accommodate height of large wheelchair
Full length bench seats in rear for extra passengers
Electric retractable ramp, slides under van smoothly
Extra power and rear Air conditioning vents- heavy duty engine and battery
Sliding cargo door, slides into frame
Bay view, extra large windows with pull-down shades.

This van was converted by Mobility Concepts, one of the few facilities doing this type of van conversion in the South Florida area. New, this van and conversion would cost $40,000 -$45,000. I am selling this van for $25,000.

Offered for sale by owner Days: (305) 252-6915
Eves & week-ends:

Doubling your Donation

Does your company have a matching gift program?
If so, you could double your donation.
Many companies match the cash gifts given by their employees.
Check with your employer to see if the donation you make to us can go twice as far.

SI USTED NECESITA INFORMACION EN ESPANOL
somos de la comunidad, por favor comuníquese con nosotros y con mucho gusto se la daremos.
Llamenos al 305 243 7400
En nuestro web-site tiene la posibilidad de traducir la información de Inglés a Español
www.miami-als.org

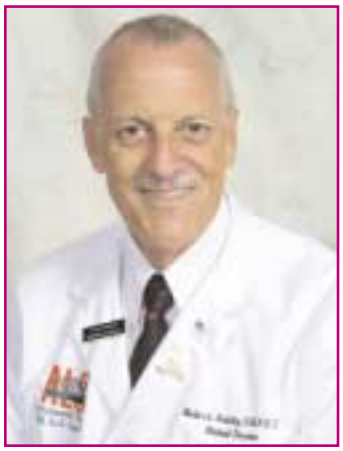
Presented by Neff Rental, The Florida Marlins, and Pharmed Group







This year's Golf Classic at the Doral was attended by more than 300 people, including golfers and volunteers. This was a very successful event, thanks to every one's hard work, particularly the Perez family and friends. We thank everyone for their tireless efforts.



Advances in ALS from the 14th International Symposium
Milan, Italy
November 17-19, 2003

The 14th Annual ALS/MND Meeting in Milan was probably the largest such meeting ever, with more than 700 participants, including physicians, scientists and lay people. Over 900 papers and abstracts were presented. Information on this is available at http://www.mndassociation.org, and slides of this presentation at the Kessenich Family MDA ALS Center Annual Symposium on December 13, 2003 are on the website [www.als-miami.org].

Clinical Studies

Epidemiological data presented by Dr. E. Beghi suggested that there may be an increasing incidence of ALS, particularly in women. Dr. Stefano Belli presented information that ALS appears to be occurring twelve times as frequently as would be expected in former Italian professional soccer players. We are planning an epidemiological study of the frequency of ALS in Dade County, and hope eventually to expand this to the whole of Florida.

Cognitive disorders are being increasingly recognized in patients with ALS, particularly those with bulbar onset. A number of papers were presented at Milan of subtle changes that can be detected by neuropsychological testing. We have a neuropsychological research study being undertaken by Dr. Alison Grossman in the Kessenich Center.

Caregiver burden was addressed in papers by Dr. Chio of Italy and Dr. Goldstein of the United Kingdom. The physical burdens are mainly due to lack of time for the caregivers personal needs, and the psychological burden was found to be less if the caregiver had strong religious views. Despite much research, I do not think we have information that truly represents the burden borne by caregivers of ALS patients.

Depression in ALS patients and caregivers was studied by Dr. Alberts from New York, indicating that the prevalence was only 5-10%. I think that reactive depression, which perhaps does not reach the full criteria for psychiatric diagnosis, is much more common, and can benefit from treatment with medications.

The management of ALS was reviewed in a paper that I presented on behalf of the ALS Care Study Group. This has improved significantly since the publication of the American Academy of Neurology ALS Practice Parameter in 1999. The use of anti-depressants for emotional lability, and medications to reduce excess saliva has increased significantly. The use of gastrostomy to prevent aspiration pneumonia and maintain nutrition, and noninvasive positive pressure ventilation [BiPAP] have all increased significantly, though still the majority of patients do not receive these important methods of management of the disease. Nearly two-thirds of patients are now taking Riluzole. Almost half the patients not taking Riluzole found it either too expensive or did not think it was of benefit. Recent evidence indicates that the benefit from Riluzole is about a 30% slowing down of the rate of progression of the disease. A paper by Dr. Groeneveld from the Netherlands studied Riluzole blood levels and showed that the higher the blood level the better the rate of slowing of the disease. They used doses up to 300mgs [6 tablets] per day to reach these blood levels.

Stem cell research was highlighted by a paper by Dr. Mazzini from Italy, who reported on the injection of bone marrow stem cells into the spinal cord of five patients with ALS. There was no damage seen, but no benefit was observed. Many of the physicians and scientists at the meeting felt that Dr. Mazzini had gone beyond what was ethically justified at this stage in our development of knowledge of stem cells.

Several new drug trials were reported at the Milan meeting. The creatine trial, which was also undertaken at the University of Miami, was unfortunately negative. A phase II trial of Minocycline in New York did not show any benefit, and in fact the active group did rather worse than the placebo group. Nevertheless there are plans to expand this to a phase III trial. Tamoxifen is being used in a dose escalating study at Madison, Wisconsin. From a collaborative study of NIH and the ALS Association among others, 1040 compounds including 750 FDA approved drugs have been subjected to screening assays for efficacy in human diseases. Eight of these assays were ALS-related. Cephalosporins appear to have multiple hits, and Drs. Merit Cudkowicz and Jeremy Shefner are developing a research study of ceftriaxone [Rocephin]. This will however be a very difficult study, since the drug has to be given by intravenous injection twice daily into a catheter for six months or longer.

Basic Neuroscience Research was highlighted by several exciting new discoveries that have been made relating to ALS. Three new proteins have been discovered to be involved in moving material up and down the axons of motor neurons. These are dynein, dynactin, and dynamitin. Mutations of the genes for these proteins cause motor neuron degeneration, and may be responsible for some cases of familial ALS. Dr. John Glass of Emory University in Atlanta presented evidence that the distal branches of the motor neurons are the first to die in the SOD1 mouse that is a model for ALS, and saw a similar pattern in one early ALS patient.

Drs. Cleveland from the United States and Julien from Canada have studied chimeras of mice with ALS due to introduction of the mutant human SOD1 gene. Mutant protein has to be in both the motor neurons and the supporting cells of the spinal cord before motor neuron disease develops. Even 20% of normal supporting cells can prevent the motor neurons degenerating. This offers the possibility for arrest of the disease with stem cell treatment when eventually we can make these cells survive in the spinal cord.

There was much work on the basic science of protein aggregation that is important in ALS. These protein aggregates precipitate in the cells, and our work has demonstrated impairment of mitochondrial function as a result. There are a number of proteins such as ubiquitin and heat shock proteins that can be up-regulated in the SOD1 mouse, leading to improved survival.

The second gene for familial ALS, ALS-2, was recently identified. This is responsible for the juvenile form of ALS that is commoner in North Africa. The gene incodes a protein that is involved in intracellular signaling and transport. Attempts are being made to create a mouse model of this gene to allow a full understanding of its importance.

New MRI studies have been able to show some evidence of metabolic changes in the motor neurons of the brain of ALS patients, and the University of Miami has been active in this type of study. Transcranial magnetic stimulation has also been used to investigate the motor neurons of the brain, and does show evidence of abnormal function of those neurons.

Summary

The Milan 2003 ALS MND meeting was very busy, and a great deal of new information was exchanged between the participants. A number of new clinical trials are planned and much new research was stimulated. The next meeting will be in Philadelphia on December 2-4, 2004. These meetings are open to lay people who wish to hear what is going on, and to take part in the clinical sessions. If you would like to attend the Philadelphia meeting, contact the Kessenich Family MDA ALS Center and we can give you information.

Walter G. Bradley, DM, FRCP Medical Director

Walid and Chafnaze Hassoun

Walid was born in Palestine on Oct. 24th, 1947. Chafnaze was born in Lebanon on Nov. 22nd, 1953. They have been married since March 28, 1971. Walid used to work in UAE and Nigeria with a Construction Company in the engineering field. He was a good worker and he liked his job a lot. They moved to the US twenty years ago, and have been living in Florida ever since.

Walid and Chafnaze travel a lot; they have traveled through most of Europe, and most of the States in the US. It is unfortunate that they can no longer travel because of Walid's illness; by the way, the Hassoun's don't have any children, but are happy in their life. Walid likes sports a lot and he used to play soccer in Lebanon.

In 1989 Walid noticed that his hands started to become weak. In 1991 he found out that he could not move his left thumb. He went to a neurologist and many tests were conducted on him. Walid was diagnosed with ALS. He then asked Dr. Gerald Goldberg "what kind of disease is ALS?" Once Dr. Goldberg explained everything to Walid, he was shocked. As Chafnaze said: "we could not do anything. Life is very hard, and we all have to take the good with the bad. We have faith in GOD and that he will help us live our lives." In April of 1996, Dr. Gerald Goldberg sent Walid to see Dr. Walter Bradley.

The disease is slowing down and Walid enjoys going to the park to watch the games. He goes by himself on his scooter, thanks to the Kessenich Family MDA/ALS Center and the ALS Association. They have helped with everything from equipment to medications. "Walid & I cannot thank you enough for all of your support and we feel like they are our family, GOD bless them all." Chafnaze is the caregiver for Walid and she is so happy to take care of him. She does everything for him, because he cannot use his hands that much. She tells him that he is her big baby. "When our families heard about Walid, they felt very bad. As I said before, this is life and it is not in our hands. We can't change it; we have to live with what God gives us."

"Walid likes to go to the support groups. Sometimes we go to Miami and sometimes we go to Weston. We have family and friends here and we do activities together. We have relatives almost all over the world and we mean everywhere. Our love goes to all of them; we wish them all good health. We wish for peace and love in the whole world. Good luck to you all."

Walid and Chafnaze Hassoun

ANNUAL ALS SYMPOSIUM

Our Annual ALS Symposium was a great success, thanks in part to our wonderful guest speakers: Ashok Verma M.D., who spoke about Respiratory Care in ALS; Lawrence Baches, Attorney at Law, who spoke about Disability and Pension Benefits; Jean Hill, our Physical Therapist, who informed our patients and their families about Home Safety. Laura Guzman, our Occupational Therapist, spoke about Upper Extremities, Condition and Exercise. Mary Ellen Kayata our Speech Pathologist did an excellent job talking about Effective Communication and Safe Swallowing. Morton Getz, M.D., introduced Hospice to our patients and their families. Dino Scanio spoke about ALS Orthotic Braces. Last but certainly not least, Walter G. Bradley D.M., F.R.C.P. updated us on his trip to Milan, Italy were he attended the International ALS Symposium.

Over 130 people, including patients and family members, attended our Annual ALS Symposium.
Because of them, our wonderful staff and volunteers and sponsors, this was a memorable and successful event.

My Book Of Recipes

CREAMY SHRIMP AND NOODLES

1 cup onion, finely chopped.
1 1/2 cup green pepper, finely chopped.
1 cup tomatoes, drained and finely chopped.
1 1/2 pounds shrimp, finely chopped.
3 tablespoon margarine, melted.
1 tablespoon paprika.
1/4 teaspoon pepper.
1 cup sour cream.
13 ounce package cream cheese, cubed.
18 ounce package thin noodles, cooked and drained.

DIRECTIONS:

1.Cook onion, green pepper, tomatoes and shrimp in margarine in large skillet over medium-low heat for 20 minutes, stirring occasionally.

2.Add seasonings, sour cream and cream cheese, mixing well.

3. Continue to cook until cream cheese is melted, stirring constantly.

4. Do not boil, stir in noodles.

Makes 8 servings.

THE BERRIES

1 cup strawberries.
1 10 ounce package frozen raspberries, thawed.
11/2 cups cold milk.
1 (8 ounces) container vanilla yogurt.
2 eggs.
1/4 cup honey.
1/2 teaspoon vanilla extract.

DIRECTIONS:

1. Place strawberries, raspberries and 1/2 cup milk in a blender container.

2. Blend on high speed for 1 minute or until smooth.

3. Add remaining milk and other ingredients.

4. Blend until frothy, serve immediately in tall, chilled glass.

Makes 3 servings.

Announcements

Friend of a Friend ALS Foundation Tampa Conference

The Friend of a Friend (FOF) ALS Foundation is hosting a free one-day educational conference addressing some of the issues facing ALS patients, their families and the doctors who treat this disease.

The conference will be held on

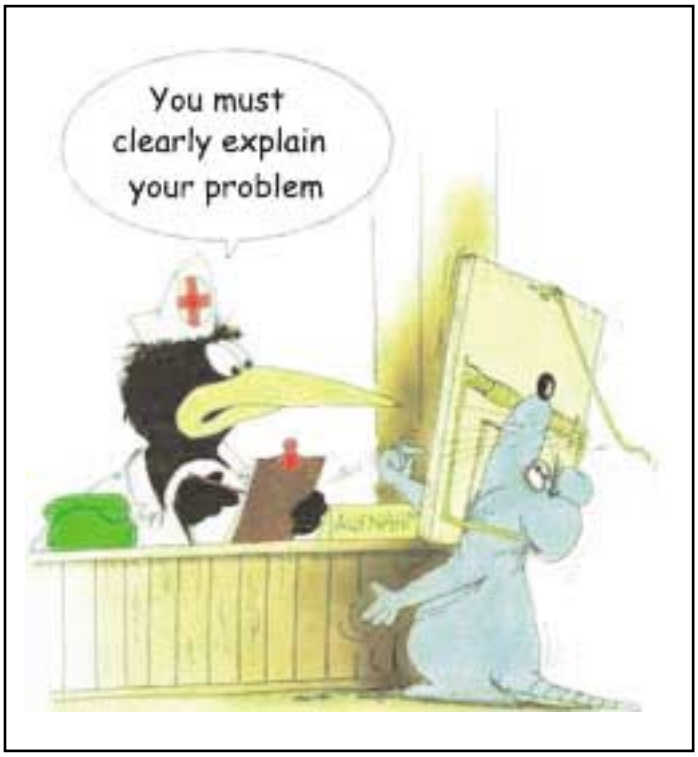
Saturday, April 3rd, 2004 from 9:00 a.m. – 3:30 p.m.

at the Diagnostic Center at St. Joseph's Hospital in Tampa, FL.

Guest speakers from the medical community will be presenting on topics such as orthotic bracing, speech/occupational therapy, accessing disability benefits and hospice services, all of which are specific to the needs of ALS patients.

We are pleased to announce that Dr. Verma, from the University of Miami ALS Center, will be presenting a brief lecture on respiratory care for ALS patients. Vendor displays from companies in the industry and representatives will be available to answer your questions.

If you are interested in attending the conference or would like to register for the event, please contact Dino Scanio at (813) 477-1219 or e-mail the FOF Foundation at fofalsfoundation@aol.com. The deadline for registration is March 19th, 2004.



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@lucy.net.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.**

The Kessenich Family
MDA ALS Center
1150 N.W. 14th Street (M-712)
Suite 701
Miami, Florida 33136

Non Profit Org.
U.S. Postage
PAID
Miami, FL
Permit Nº 438

Calendar

ALS Support Group Dates For The Year 2004

Saturday, March 13 (Memorial Day)
Saturday, April 17
Saturday, May 8
Saturday, June 12
Saturday, July 10
Saturday, August 14
Saturday, September 11
Saturday, October 16
Saturday, November 13 (Thanksgiving Luncheon)
Saturday, December 11 (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 talks by our doctors and therapists, and different healthcare companies and providers 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.**

ALS Recovery Foundation Walk-a-thon April 24, 2004

Directory