

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

Volume 7 • Issue 1 • Fall 2005

The official newsletter of the University of Miami ALS Center

Kessenich Corner

Our new clinical site



ALS Neurologists



Walter Bradley, DM, FRCP



Ashok Verma, MD., DM.

Dr. Walter Bradley and Dr. Ashok Verma have special expertise in diagnosing, evaluating and managing patients with ALS and other neuromuscular diseases. The initial role of the Neurologist is the medical evaluation of the patient and diagnosis or confirmation of diagnosis. Physicians handle all medical questions, identify pressing issues, discuss the latest developments in ALS research and offer the patients the opportunity to participate in clinical research trials.

ALS Registered Nurses



Ginna Gonzalez, RN, BSN



Graciela Reyes, RN, BSN

Ginna Gonzalez and Graciela Reyes work in conjunction with the Neurologist and the multidisciplinary team to provide support and coordinate health care to improve the patient's quality of life. The Nurses are also the liaison between The Kessenich Family MDA ALS Center staff and hospice care providers, primary doctors, insurance company case managers, MDA and ALS associations. Nurses also provide comprehensive patient and caregiver education.

Physical Therapists



Sabrina Camilo, PT., M.S.P.T



Tammy Tyrakowsky, PT

Physical Therapists specialize in restoring and maintaining function, pain management, gait training and exercise. PT's make recommendations about home exercise programs, assistive devices such as walkers, canes and other orthosis as well as wheelchair adaptations.

Speech Language Pathologist



Erika Sauer, MS., CCC-SLP.

The Speech Language Pathologist specializes in the treatment of swallowing problems. SLP's provide compensatory techniques to improve speech quality as well as augmentative and alternative communication devices to maintain independent communication ability. The Speech Language Pathologist works closely with the nutritionist to recommend effective strategies for swallowing.

Respiratory Therapist



Salome Gozon, CRTT & Terri I. Zeitz, RRT

The Respiratory Therapist evaluates the pulmonary function of the patient and recommends non-invasive ventilation or permanent ventilation. The Respiratory Therapist can help patients and families learn about the many ways to enhance breathing and the indications for and implications of each alternative.

Nutritionist



Clover Coulton-Smith, DTR

The Nutritionist performs assessments of nutritional status, regularly evaluates appetite, weight and recommends if feeding tube (PEG) is required. The Nutritionist works closely with the Speech Pathologist to determine the degree of dysphagia and recommends strategies to modify food preparation and swallowing.

Psychologist



Barbara Simmonds, PhD

The Psychologist provides counseling to patients and families and assists in coping with the effects of ALS. The Psychologist is there to listen and to help the patient and family adjust to the diagnosis and the functional changes as they occur.

Case Manager

Enrique Maspons, CM

Case Management is a collaborative process that assesses, plans, implements, coordinates, monitors and evaluates options and services to meet an individual's health care needs. The Case Manager assesses the social and financial resources of the patients and provides information about disability and community services.

MDA Patient's Coordinator



Denise Castro

The Coordinator serves as a liaison between patients and the ALS clinic. She helps them obtain services from community resources and is a patient advocate.

Recent Drug Advances IN ALS



Dr. Steven Resnick, D.O.

The past decade has seen a dramatic expansion in ALS pharmaceutical research. The University of Miami Kessenich Family MDA ALS Center is up to date on the most recent advances and treatment strategies. Most patients with ALS tend to have very similar questions. Mainly, are there any new medications to slow the progression of ALS? And also, how can they participate in an ALS clinical trial? This article summarizes the most

current advances in medical treatment. Useful web resources for further information on the latest clinical trials for ALS are also provided.

One of the hypotheses for the pathogenesis of ALS is the excess glutamate that causes excitotoxic damage to motor nerve cells. Riluzole, an inhibitor of the excitatory neurotransmitter glutamate, is currently the only medication approved by the Food and Drug Administration (FDA) for slowing the course of ALS. Riluzole is most likely underutilized due to the high cost of the medication and some side effects.

Another medication to enter soon in human clinical trials is ceftriaxone. Cephtriaxone is a beta-lactam antibiotic related to penicillin. In one blinded screen that tested about 1040 FDA-approved drugs and nutritional supplements, cephatriaxone was found to be effective in cell models with excitotoxic nerve cell injury. It appears that cephatriaxone helps increase glutamate mapping by the supporting cells (astrocytes) in nerve cell neighborhood. Laboratory evaluation using the ALS mouse model has found ceftriaxone to prolong survival. A small preliminary study in humans is currently being designed to evaluate the safety of the drug, before opening enrollment to a larger clinical trial to determine the clinical efficacy of ceftriaxone. Other presumably anti-glutamate medications, including gabapentin and topiramate, sadly failed to benefit patients with ALS.

Tamoxifen is commonly prescribed for women with breast cancer. The drug works against breast cancer, in part, by interfering with the activity of estrogen on tumor cells. Physicians from the University of Wisconsin serendipitously noted that patients with ALS and breast cancer who

were on Tamoxifen had a slower form of ALS. Its favorable survival effect was later observed in the mouse model of ALS. Dr. Benjamin Brooks from the University of Wisconsin then led a study using riluzole with the addition of tamoxifen. This small study using sixty patients demonstrated clinical benefit at three highest doses tested at 24 months. Dr. Brooks found that participants who took more than 20 milligrams of tamoxifen a day had a better survival rate than those who took fewer than 10 milligrams a day. After two years, 27 out of 37 (73 percent) of the participants in the high dose tamoxifen group survived, while only 11 out of 23 (48 percent) of those in the low dose were still living. At this time, a larger clinical trial is being planned to confirm the survival benefit of tamoxifen in ALS.

Coenzyme Q10 (CoQ10) is a mitochondrial cofactor that participates in cell energy pathways. Mitochondrial alteration and possible cell energy failure has been contemplated in ALS. CoQ10 is thought to improve mitochondrial function and therefore can potentially slow ALS progression. Recent data has shown that CoQ10 improves disability in Parkinson's disease. Two small studies at Columbia University demonstrated that doses up to 3,000 milligrams were safe and well tolerated in patients with ALS. Due to the open-label study with a small sample size, the survival benefit was difficult to assess in the Columbia study. At this time, the National Institute of Health has granted funding for a larger study to evaluate CoQ10 in ALS. CoQ10 is available as a nutritional supplement over the counter.

Minocycline, an antibiotic in the tetracycline family, is found to delay onset and slow progression of symptoms in the ALS mouse model. Minocycline is thought to work by blocking release of a molecule that triggers cell death pathway. Minocycline is currently being tested against a placebo to determine the safety and effectiveness in ALS.

To find out more information about ongoing trials, the following list of websites may be useful. The ALS association (ALSA) at www.alsa.org, Muscular dystrophy Association (MDA) at www.mdaua.org, the National Institute of Neurological Disorders and Stroke at www.ninds.nih.gov, and the ALS Therapy Developmental Foundation (ALSTDF) www.als.net. For local information, contact the Miami ALS center at www.miami-als.org.

News for Veterans

Safety and Dose Escalating Study of Oral Sodium Phenylbutyrate in Subjects with Amyotrophic Lateral Sclerosis

Currently Enrolling

Details:

Primary Outcomes: The ability to complete the dosage increase and maintenance phase at 21 grams per day

Secondary Outcomes: The number of side effects of each dosage, including abnormalities in vital signs, physical examination, blood tests and EKGs, change in vital capacity (breathing function) and ALS functional rating scale; Relationship between blood levels and sodium phenylbutyrate dosage

Expected Total Enrollment: 40

Study begins: April 2005

Although it is known that nerve cells die in the brains and spinal cords of patients who have ALS, the cause of the cell death is unknown. There is evidence that this cell death may be caused by changes in DNA, the body's genetic material. Drugs such as sodium phenylbutyrate (NaPB) can increase the expression of genes, block how the motor nerve cells in ALS die and may prove to be an effective therapy for ALS. NaPB has shown an improvement in survival in mice with conditions similar to ALS. All research participants will take sodium phenylbutyrate for a total of 20 weeks. The dose of medication will be increased every 2 to 4 weeks until a maximum, easily tolerated dose is achieved (study maximum is 21 g/day). Non-Randomized, Open Label, Uncontrolled, Single Group Assignment, Safety Study

Inclusion Criteria:

- Diagnosed with ALS
- At least 18 years of age
- Women, who can become pregnant, must actively use effective birth control measures

Only veterans with ALS may apply for inclusion in trials located at VA medical centers.

Exclusion Criteria:

Must not have any other neurological (nervous system) disease

Location and Contact Information: Patricia Loya, 781-687-2884,

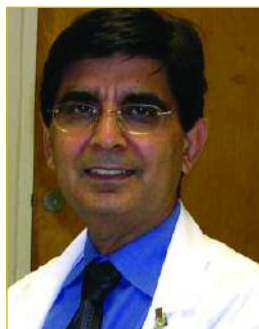
Patricia.Loya@med.va.gov

Sally MacDonald, RN, 781-687-2963,

Sally.MacDonald@med.va.gov

For a full list of study locations, please visit The ALS Association web site at www.alsa.org/patient/drug.cfm?id=629.

Basic science research brings new rational clinical trial of ALS



Ashok Verma, MD, DM

by Dr. Ashok Verma

Approximately 20% of patients with familial ALS have mutation in SOD1 gene that causes the disease. It is now clear that transgenic rodent models harboring copies of the human mutant SOD1 gene predictably develop the disease very similar to ALS. In SOD1 rodent models, one key process that appears to contribute to the cell death is misfolding and aggregation of the mutant

SOD1 protein and its deleterious binding to

other essential cell proteins. Excitotoxicity and impaired axonal transport and energy pathways also contribute to cell demise in these animal models. Most ALS clinical trials in the past have been focused on ways to combat excitotoxic cell damage, attempts to rescue sick cells using nerve growth factors and strategies to support cellular energy pathways. Sadly, clinically meaningful success has eluded us from these lines of research so far.

Recently, some ALS researchers have focused their efforts in devising strategies to prevent or reverse misfolding of proteins, the apparent key step in the cascade that eventually results in motor cell demise in familial and perhaps sporadic ALS. Stress proteins or chaperones (also called 'heat shock proteins') are essential cell proteins that help form and maintain proper conformation of proteins. Heat shock proteins are known to promote cell survival after a variety of environmental stresses.

Arimoclomol, a small molecule, is a strong inducer of chaperones and heat shock proteins and elevated levels of these proteins can potentially rescue sick nerve cells. In a recent report, a research team led by Dr. Linda Greensmith in the United Kingdom, reported that arimoclomol significantly delayed disease progression in mice expressing human mutant SOD1 protein. Most importantly, and for the first time, it was shown that arimoclomol prolonged the life span in ALS mice models even when it was administered after the onset of the weakness. The robust effect of arimoclomol showing 22% increase in life span was greater than that of any other chemical tested so far in this mouse model of ALS.

Pharmacological upregulation of the chaperones and heat shock proteins by arimoclomol may therefore be a more successful therapeutic approach to treat familial and sporadic ALS.

Dr. Merit Cudkowicz at the Massachusetts General Hospital Neurology Clinical Trials Unit, in collaboration with other ALS centers in the country, has designed a phase IIb arimoclomol clinical trial in patients with ALS. A group of 80 patients are being enrolled in this trial at 10 ALS centers. University of Miami Kessenich Family MDA-ALS Center is participating in the arimoclomol multi-center clinical trial. We are currently recruiting ALS subjects to participate in this study. For further information about participating in the arimoclomol clinical trial, please contact Dr. Donald Koggan (305) 243-7424 at the University of Miami ALS clinical trials division.

A Day with Special People



Mary Ellen Kayata, M.S., CCC-SLP

By: *Mary Ellen Kayata, M.S., CCC-SLP Speech Pathologist*

I was fortunate to visit both John Lore and Darlene Bunch in the month of April. They welcomed me and two of my colleagues and shared some valuable information that I would like to pass on to others who may be in need of augmentative communication. This information is especially helpful for those patients experienc-

ing difficulty with upper extremity movement.

There is a hands free mouse available made by Natural Point called Smart NAV 3 AT. (www.natural-point.com) It costs approximately \$400, however Tracey Lore reports that a discount can be requested.



The reflective piece (which is tracked by another piece that is mounted on top of the computer) can be placed on a cap, eye-glasses or pretty much wherever is convenient for the user. This can serve as the sole mouse by using the dwell click option or it can be used in conjunction with a footswitch, which can facilitate the left and right clicks.

Both John and Darlene navigated the internet quite effectively using this product. John pays all his bills and Darlene likes to access E-books so that she can fulfill her passion for reading. John informed us of an autofill feature that comes with the free Google toolbar (<http://www.google.com/downloads/>). This allows the user to fill in all pertinent information necessary for many web sites such as name, e-mail address, credit card number, etc. The information is saved and can be inserted with ease as needed. Using favorites is also another handy shortcut.

We learned of a couple of options for free on-screen keyboards. Click-n-type (<http://www.lakefolks.org/cnt/>) provides the standard keyboard where as dasher



(<http://www.infer-ence.phy.cam.ac.uk/dasher/>) provides a different set-up with the letters flashing across the screen. Both have word prediction. (Bringing up several word possibilities once a word is being typed) Dasher provides voice once you open it, then click "options", then "control mode". This will cause an additional gray "control" box to appear at the bottom of the letters on the word capture screen. After you enter a few words into Dasher, you steer to the gray "control" box and then the light gray "speak" box. Dasher should speak all of the words that you have previously spelled that are in the white text entry area near the top of the screen. Most newer computers have the ability to produce voice through

"narrator". You access this through "programs" to "accessories" to "accessibility" to "narrator". Once you start "narrator", the computer will state every move you make, including every letter you type. The downside is that the listener hears the word spelled out as opposed to the entire word. There may be a way around this, but we have yet to figure it out.

WindowsMedia Center 2005 is a wonderful program (available through Microsoft) that allows you to achieve access to many parts of your environment using the head mouse. The DVD, radio, alarm clock, photos, music, telephone and television can all be accessed without the necessity of upper extremity movement. These are just a few things that I learned from John and Darlene after spending a couple of hours with them. Chances are they have already discovered other ways the computer can help us. I thank them for allowing us into their home and helping me to pass on what they have learned in their own exploration to make their communication more effective and their days more enjoyable. I hope that some of you can benefit from this information. Please feel free to share anything that you have learned as well.

Additional Switches

Pillow Switch

This round switch can be pinned to a pillow and activated by a controlled head movement.



Wobble Switch

Activated by gross body or head movements coming from any direction.



Rocking Lever Switch

Activated by gross hand, arm, or body movements, or by a mouth or head stick



Sip or Puff Switch

This switch requires sipping or puffing on a tube. Minimal pressure changes are necessary. Breath control vs. respiratory control required.



P-Switch

Activated by minimal movement detected by small sensors which can be placed on any part of the body capable of minimal motion. The sensitivity of activation can be set by the user. Replaceable 9 volt alkaline battery, Velcro™ accessories, two sensors, two mounting bands, connecting cables, and manual are included.



Holiday Cards Available: ALS Gallery Collection



Humberto Benitez

It is our pleasure to announce the artist of this year for the ALS Gallery Collection, Humberto Benitez. He donated one of his prestigious paintings to be part of this ALS Gallery Collection.


Gables artist Humberto Benitez, Cuban exile, believes that the United States introduced him to a whole new world of color. The self-described “explosion of human emotions” has made great use of color in his exploration and interpretation of life, as seen through someone who developed his artistic eye in the Cuban countryside.

“Inspiration comes from my heart and my homeland. It is the core of my emotions. My paintings are filled with vibrant colors and texture. The greens of my home land are unlike any green in the world. It was a place where nature filled the soul, where the magical blue sky and majestic royal palms embraced the landscape. I grew up in this magical place that transforms a person and stamps the inner core of your heart with unforgettable memories, thoughts and feelings.”

“Painting is much like learning to see for the very first time,” Benitez says. “The (Cuban) soil was pure volcanic red, this soil seems to run through my veins.”




Winter Home Item #7



Inside: Greetings of the Season and Best Wishes for the New Year

Monty Topolche Item #8




Inside: Happy New Year

Monty Topolche has only been painting for 10 years. His watercolor paintings have won blue ribbons for four years in a row at the annual Senior Citizens Art Show and Auction in Fort Lauderdale. His work is displayed in taverns at local restaurants and at the cultural center where he lives. "I took up painting after I retired," he said. "I need to do



Angel Item #1




Inside: May your heart be filled with the warmth of these Holiday Seasons.

Art Work donated by Romero Britto.

"As a child growing up poor in Brazil, I was introduced to the darker side of humanity. The result was, I started painting to bring light and color into my life. I know that there are still terrible things happening around the globe. I do not want to repeat what I see on the front page in my art. To me, that would only perpetuate the sadness in our world. I was born to paint life in a different way, rejoicing in the beauty our world has to offer. The world I paint is an explosion of positive optimism, and happiness that so many of us are looking for these days!"

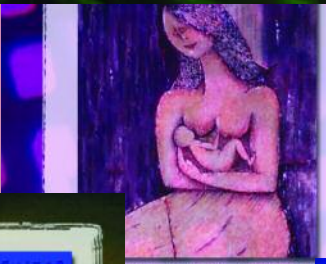
Daphne Item #2



Inside: May the Peace and Light of the Holiday Season Fill your Year with joy.

Art Work donated by Sebastian Spreng, Argentinian.

After a successful career in his country, the Argentinian born artist moved to Miami in 1987 and has been a strong presence in the Florida art scene ever since. Spreng's works have been seen in a group exhibitions throughout the United States as well as in Germany, Japan, Central and South America. Many of his pieces were chosen as cover illustrations for the Florida Philharmonic Playbills as well as the NEWS 1997-00 Season Program Book. He was the first local artist to be asked by the Florida Grand Opera to create the Season Poster (1998-99).



Hanukkah Item #4

Happy Hanukkah



Peace on Earth Item #5



Inside: May the Peace and Light of the Holiday Season fill your year with joy

Art work donated by Cenk Sengul

Cenk Sengul is young physician from Turkey. At present time he is working in the neurovascular research at the University of Miami. He uses his free time to created beautiful art. As a child he was recognized and received several prizes in his country.

Snowman Item #6

Let our hearts Be Joyful



Inside: Have a bright and Happy Holiday Season.

all the Seasons of your Life be filled with and Hope.

donated by Nydia Sanchez Franco.

ainter, sculptor, graphic artist and ceramic on exhibited throughout the United States in Paris, Denmark, Germany, Central and ca.

son for her great versatility, incredible and has caught the attention of collectors world. The joy and enthusiasm that Nydia all her works are signature to the graceful exemplifies the beauty of her artistic style.



For More Information about our Holiday Cards
Please call 305-243-7400

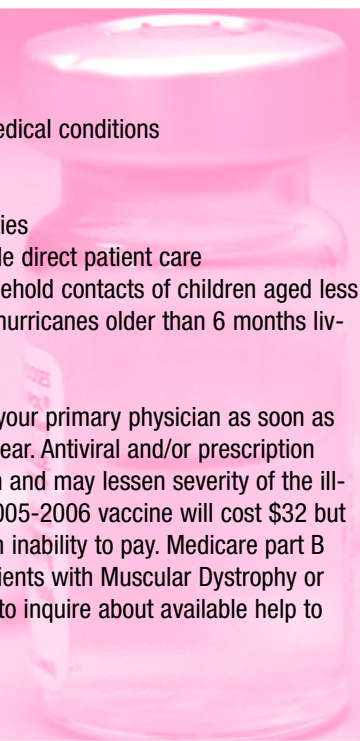
Flu Vaccine

Flu season is here once again. This year flu season starts as early as October and lasts until late May. Although immunization against influenza is most important for those at increased risk for complications from flu (adults 65 years of age or older, individuals with chronic health conditions or who are more than three months pregnant and children 6-23 months old). Healthy adults should also consider immunization. Those at high risk should try to receive their vaccinations early in October while healthy adults may wait until after October 24th, 2005. Flu shots are available at many Physician's offices. Additional information about the Flu season is available at the Centers for Disease Control and Prevention's Web site, www.cdc.gov/nip/flu/

With the uncertainties regarding available influenza vaccine doses and distribution, the Department of Health and the Centers for Disease Control and Prevention (CDC) recommend that the following priority groups get their flu vaccine first, through Oct. 24, 2005: persons aged 65 years and older;

- persons aged 2-64 years with medical conditions
- children aged 6-23 months
- pregnant women
- residents of long-term care facilities
- health-care personnel who provide direct patient care
- out-of-home caregivers and household contacts of children aged less than 6 months evacuees of recent hurricanes older than 6 months living in crowded group settings.

It is very important to consult with your primary physician as soon as the first symptoms of influenza appear. Antiviral and/or prescription drugs, can help reduce the duration and may lessen severity of the illness if taken early. A dose of the 2005-2006 vaccine will cost \$32 but services are never denied due to an inability to pay. Medicare part B will cover the cost of shots. For patients with Muscular Dystrophy or ALS, contact your local MDA office to inquire about available help to cover the cost of the vaccine.



PRINCIPLES OF ATTITUDAL HEALING

By: Gerald G. Jamplosky, M.D.

- 1.) The Essence Of Our Being Is Love
- 2.) Health Is Inner Peace. Healing Is Letting Go of Fear
- 3.) Giving And Receiving Are The Same
- 4.) We Can Let Go Of The Past And The Future
- 5.) Now Is The Only Time There Is... And Each Instant Is For Giving
- 6.) We Can Learn To Love Ourselves And Others By Forgiving Rather Than Judging
- 7.) We Can Become Love Finders Rather Than Fault Finders
- 8.) We Can Choose And Direct Our Lives To Be Peaceful Inside Regardless Of What Is Happening Outside
- 9.) We Are Students And Teachers To Each Other
- 10.) We Can Focus On The Whole Life Rather Than The Fragments
- 11.) Since Love Is Eternal, Death Need Not Be Viewed As Fearful
- 12.) We Can Always See Ourselves And Others As Either Extending Love Or Giving A Call For Help

Mark Your Calendar!



5th Annual Lou Gehrig's Disease 10K Run and 5K Run/Walk

Saturday, November 5th, 2005
7:30 a.m. • Coconut Grove

Announcement Corner

ALS Annual Symposium

The Kessenich Family MDA ALS Center and
The University of Miami

*Cordially invites you to
attend our
Annual ALS Symposium*

Saturday, December 17, 2005

Time: 11:00 am to 3:00 pm

Sheraton Miami Mart Hotel
East Hall

711 NW 72 Avenue
Miami, FL 33126

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How to help Children through a parent's serious illness

You must tell children the truth.

Your children are affected by everything that happens in the family. Being honest can be painful. Nevertheless, dishonesty, even with the honorable goal of protecting the children, may be the single biggest mistake you as a parent can now make. There may be nothing more important in their lives than that they continue to trust the two people they love most- the parent who is sick and the parent who will continue to care for them.

Children are stronger than you think. Because they love you, they can handle what is coming. What we must do now is build on that love and build that strength.

Three things to tell your children

- Tell them you are seriously ill.
- Tell them the name of your disease.
- Tell them your best understanding of what may happen.

However grave the illness, hope comes along with every diagnosis. And it is neither wrong nor dishonest to pass this hope along to your children.

Something to think about now

All life is terminal. Even if one's own timetable is tragically shortened by a medical diagnosis, the end is not yet. There is still time, time for children and parents who love each other to make the most of. Don't try to shield your children from making the most of that time.

Explain the disease on the child's level

Tell them three things, and keep telling them:

- Nothing they did caused the disease
- They can't catch the disease from you
- Who'll take care of their needs, who will do the "Mommy things" or the "Daddy things" now.

Making time for your kids when you don't have time

- Set aside a time - ten minutes at night around bedtime and bath-time.
- Try to keep doing the family things you all do together, take a bike ride or walk to the park, etc.

Important warning signs that a child needs help

- Major changes or disturbance in sleep.
- Major changes or disturbance in eating.
- Appearance of fears that weren't there before.
- Developmental trouble: loss of skills, falling grades, etc.
- The quiet child.

Information taken from the book "How to Help Children Through a Parent's Serious Illness" by Kathleen McCue, M.A., CCLS.

Chicken Casserole

Ingredients

- 6 cooked chicken breasts, finely chopped
- 2 cups of cream
- 2 cups mushroom soup
- 1 teaspoon worcestershire sauce
- 1 4 ounce can mushroom, drained and finely chopped
- 1 6 ounce box stuffing mix

Procedure

1. Place chicken in bottom of buttered casserole.
2. Mix sour cream, soup, Worcestershire sauce and mushrooms.
3. Pour over chicken.
4. Prepare stuffing mix according to package instructions; cool.
5. Spread over casserole.
6. Bake uncovered at 350 degrees for 30 minutes.

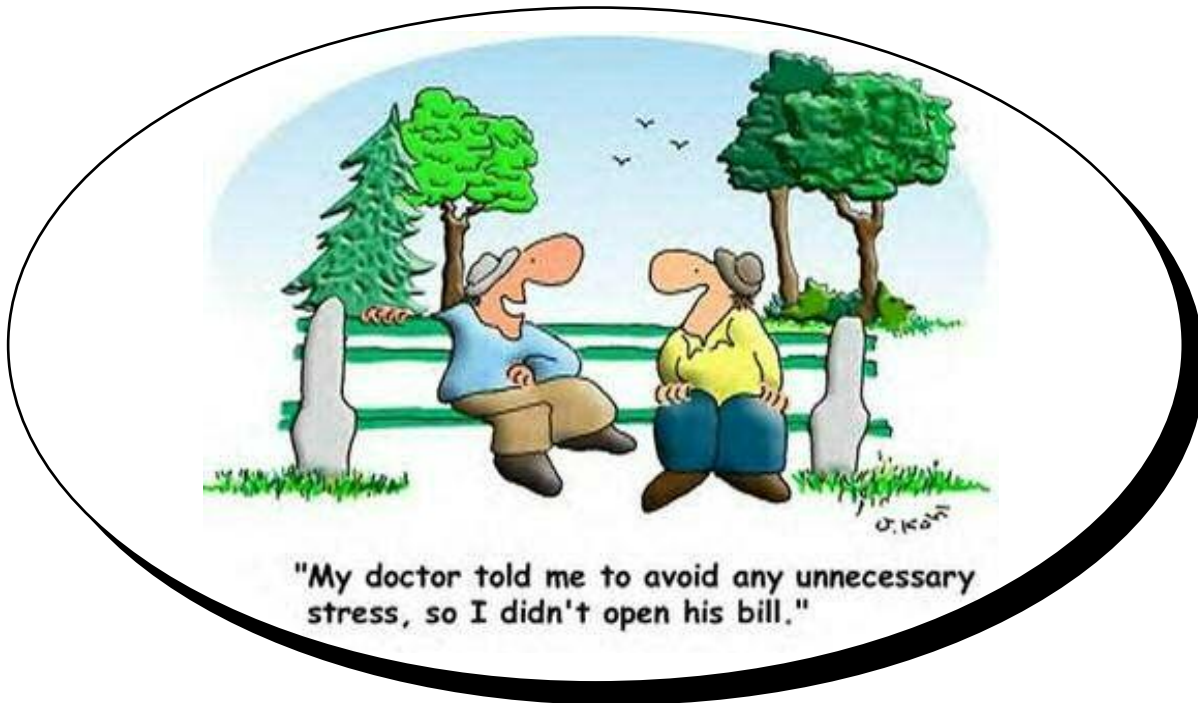
Creamy Banana Pudding

Ingredients

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

Procedure

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



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.mdaua.org
• St. Petersburg	727-576-5202 or 1-800-393-8552
• Palm Beach Gardens	561-242-5084 or 1-800-289-0535
• Broward	954-757-4390 or 1-800-572-0085
• Boynton Beach	561-742-3751 or 1-877-970-9696
ALS Association	1-800-782-4747
• ALS Association of Florida	1-888-257-1717
	www.alsa.org
National Caregiving Fdn.	1-800-930-1357
National Family Caregivers Assn.	1-800-896-3650
	www.nfcares.org
Fondation 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 email to	bro@huey.met.fsu.edu

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

NOTES:

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



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 ALS Center**
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 Miami, Florida 33136

ALS Support Group Dates For The Year 2005-06

Calendar

- | | |
|--|--|
| November 12, 2005 Thanksgiving luncheon | June 10, 2006 |
| December 17, 2005 Annual ALS Symposium | July 8, 2006 |
| January 21, 2006 | August 12, 2006 |
| February 11, 2006 | September 9, 2006 |
| March 11, 2006 | October 14, 2006 |
| April 8, 2006 | November 11, 2006 Thanksgiving luncheon |
| May 20, 2006 | December 16, 2006 ALS Symposium |



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

We hope to see you at the meetings where we will have different healthcare companies and providers who 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.

Directory

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