



Kessenich Family MDA ALS Center Newsletter

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Summer, 2003

KESSENICH CORNER

This acronym stands for the Health Insurance Portability and Accountability Act of 1996. The goals of this law were to help decrease the expense of health coverage through the use of electronic transactions, to ensure the continuance of health insurance coverage and to protect the privacy and confidentiality of a person's medical and personal information. The section of this act that is most stressed at the present moment is the privacy protection and confidentiality. This section of the act allows the Department of Health and Human Services the authority to regulate what the healthcare providers and their support staff must do in order to protect the privacy and security of health information. The provisions made by this act in regards to privacy went into effect on April 14, 2003.

What does this mean for you? This new provision gives the patients more control over their personal and medical information. It also sets rules which the healthcare provider and staff must abide by in order to be able to release, receive and use medical records. It requires that disclosures be used at the time of any exchange of information.

Here at the Kessenich Family MDA ALS Center we follow standards to protect the patient's personal and health information. The standards include:

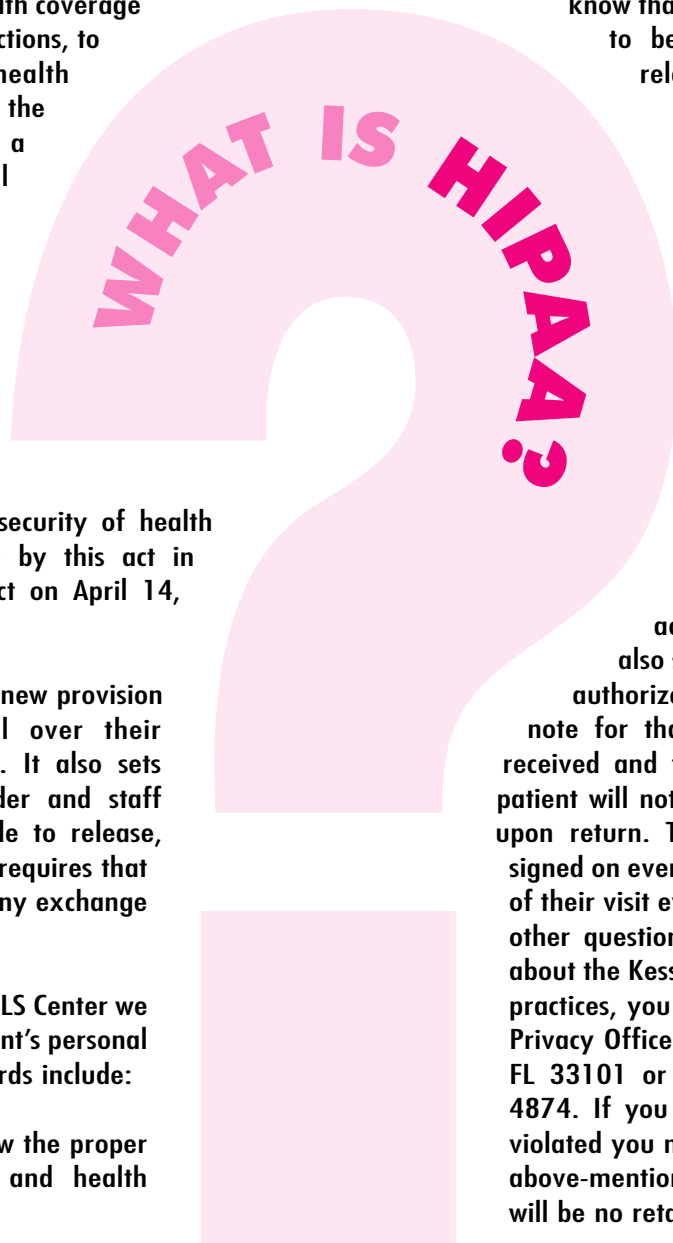
- All employees are trained to know the proper way of protecting the personal and health information of patients.

- All employees have signed a statement of confidentiality, to which they are held. This ensures the employees know that any information they come across is to be kept confidential and not to be released without proper consent.

- New forms are made and being used to ensure the proper release of any health information.

- Restriction of personal and health information to individuals who are authorized or who need to know the information in order to provide service to patients.

Remember that upon coming to a visit here at the center, the patient will be given a HIPAA booklet for which they will sign an acknowledgment of receipt. They will also sign a form called Attachment 19 that authorizes them to receive a copy of their visit note for that day. Once the booklet has been received and the acknowledgement is signed, the patient will not be required to sign this form again upon return. The Attachment 19 will have to be signed on every visit if the patient would like a copy of their visit every time they come. If you have any other questions or would like further information about the Kessenich Family MDA ALS Center privacy practices, you may contact the University of Miami Privacy Office (M879) at P.O. Box 019132, Miami, FL 33101 or at (305) 243-5000 or 1-866-366-4874. If you believe that your rights have been violated you may contact the Privacy Officer at the above-mentioned address or phone number. There will be no retaliation for filing a complaint.



DOCTORS CORNER

ALS ADVOCACY DAY ON THE HILL 2003



Walter G. Bradley, DM, FRCP

Medical Director

Kessenich Family MDA ALS Center

ALS is a "secret disease". When somebody is given the diagnosis, they and their family almost always say that they know nothing about it and know no one with it. However as they become more aware about the condition, almost everyone finds that they have a distant relative, friend or near neighbor who had the disease. The lifetime risk of getting ALS is about one in five hundred, and since each of us knows about 500 people, it is very likely that almost everyone has had a contact with an ALS patient. This is the message that your Florida delegation took to our Congressmen and Senators on ALS Advocacy Day on May 1, 2003. The Florida delegation was organized by Chairwoman, Leslie Workman and Dara Alexander, the President of the Florida Chapter of the ALS Association. Steve Hurst, an ALS patient, confirmed all the appointments. Dara, Leslie and Steve did a wonderful job to bring together a number of patients and caregivers who either are suffering from or have felt the brunt of ALS.

The 2003 ALS Advocacy Team included:

Dara Alexander	Ruskin, Florida
Dr. Walter Bradley	Miami, Florida
Dr. Barbara Bachman-Humphrey	Tampa, Florida
James Demay	Tampa Bay, Florida
Marsha Edwards	Ponte Verde, Florida
Patty Goldstein	Oldsmar, Florida
Barbara Grasc	CoralSprings, Florida
Ellen Halbstein	Boca Raton, Florida
Steve Hurst	Wesley Chapel, Fl
Gail Workman	Lecanto, Florida
Jimmy Workman	Lecanto, Florida

The delegation set out to educate the Senators, Representatives and their staff about the nature of ALS. Though the patients with ALS benefit from it being declared a rare disease, and hence having access to some governmental and nongovernmental programs [such as the National Organization of Rare Diseases], politicians always think in terms of numbers. The message about the frequency of ALS is therefore important, as well as its devastating effect upon families, their finances and their well-being.

We brought the request to our Senators and Representatives that the budget for the National Institutes of Health, particularly the National Institute of Neurological Diseases and Stroke, be increased by 8-10% in the current year, and that the Department of Defense Appropriation Bill Peer Reviewed Medical Research Program be supported. The Department of Defense is interested at this time in ALS because of the reported higher incidence of ALS in Gulf War veterans. We also urged our Senators and Representatives to support a Medicare prescription drug benefit, which will do a great deal to help a large

proportion of ALS patients receive the expensive medications, including Riluzol.

The Social Security Agency has had discussions with representatives of the ALS community, and indicated their willingness to consider rule changes that would potentially provide ALS patients with presumptive disability as soon they were given a diagnosis of ALS. Unfortunately at the present time many ALS patients are treated like patients with other forms of disability, such as stroke, where long-term survival is the rule, and a slow deliberation of adjudication of disability is accepted. Many ALS patients do not survive, or have already suffered severe financial hardship by the time they have gone through the initial rejection and appeal process before finally being awarded Social Security Disability. We made the point that this is the logical completion of the Capp Bill, which provided ALS patients with Medicare benefits one month after they receive Social Security Disability.

There is an initiative which is gaining ground in Congress to grant some form of benefit, perhaps a tax rebate, for caregivers of patients with Alzheimer's disease. We urged our members of Congress to consider an "add-on" to that resolution, which would include ALS caregivers.

The Veterans Administration hospitals are of considerable importance to ALS patients. The VA has set up a National Registry of ALS for veterans, the first in the world. This arises from their interest in the Gulf War Syndrome and ALS. The VA research grants are very important to advancing research into the cause and cure of ALS. We expressed concern to our members of Congress that there is a move in the Research Administration of the VA Central Office to close down many of the basic research grants and instead to fund research into methods of healthcare delivery, which will undoubtedly move research money away from ALS.

The Florida ALS Delegation had the opportunity to meet face-to-face with Representative Ileana Ros-Lehtinen, Representative Brown-Waite and Senator Nelson. We also had the opportunity to meet with Legislative Staff Assistants of Senator Graham and Representatives Mark Foley, Allen Boyd, Michael Bilirakis, and Kendrick Meek.

Every constituent in the State of Florida who has an interest in ALS should write, Email or call their own House Representative or Senator to bring these matters about ALS to their attention. You can find the name, phone number and Email addresses of your members of Congress by going to www.congress.org and entering your zip code. The budget is obviously tight this year with the severe recession and tax cuts. The ALS community cannot expect any of these initiatives to be successful unless we mount a very significant call-in program to our members of congress. Everyone has a voice, and we need to use it.

PATIENT CORNER

Alternative Medicine

In separate reports published in the early 1990's, both American and British medical authorities stated that alternative therapies are a mixture of different beliefs and techniques with nothing in common at all. These therapies do not necessarily replace conventional medicine but complement or support it. Alternative medicine treats nothing in isolation, stressing instead the importance of the holistic approach, seeing the mind and body as inseparable and capable of self-repair.

Alternative Medicine was the theme at our last support group. We invited different specialists:

David A. Nevins MSOM, A.P., C.H., Acupuncture Physician, and Chinese Herbologist

Dr. Silvia Casabianca, Reiki Master; Licensed Massage Therapist and Certified Trager Practitioner

Carina Wiklund, Physical Therapist

Karen Lazarus, Registered Nurse and Massage Therapist

Claudia Gonzalez, Massage Therapist Student

Eva Paglialonga, Thai Massage and Reflexology Therapist

During his presentation, David Nevins stated, "Traditional medicine describes ALS in terms of wei zhong or a wilting condition which describes muscle weakening and wasting. The condition of wei zhong involves blockages of Qi

& Blood and Qi Stagnation. Acupuncture is thought to influence the



David A. Nevins

body via the central nervous system by promoting micro blood circulation (capillary bed circulation) to the spinal cord which may promote the natural regenerative capabilities of the body. There is not enough solid clinical research to support these findings but empirical data show there is some benefit."

Acupuncture is about controlling and moving Qi (Chi). Qi is the energy that controls and regulates all body functions. Qi travels within the human body through a network of channels that follow the same routes that blood vessels, nerves, and lymph vessels do. Acupuncture points are the access sites of this network. When the Qi is out of balance, blocked, in excess, or deficient, your health is also out of balance. Acupuncture restores balance by redirecting the Qi to where it is needed. The main objectives of acupuncture treatment, according to

Dr. Nevins, are to relieve pain and related symptoms, stimulate and strengthen the immune system, and restore the homeostatic balance so you are a healthy and happy person physically and mentally.

Acupuncture can help you feel more relaxed, less fatigued and more balanced. It can be palliative and help to reduce the physical problems related to tension, stress and emotional conditions.

"Herbal therapy takes acupuncture to the next level. It is like getting an acupuncture treatment from the inside



REIKI Session

out", said Dr. Nevins. Herbs stay in the body longer and apply their effects slowly. "This is an excellent therapy for chronic conditions", he added. Make sure you consult with your doctor before you take any herbal medicine. Some are toxic when taken in large doses and some interact with other medications. Dr. Silvia Casabianca describes REIKI as one of the seven categories of Alternative Health considered by the National Institute of Health in this country.

Reiki is a Japanese word where REI means "life force energy" and KI (the equivalent to the Chinese word Qi and Indian word Prana), which means individual vital energy. When REI and KI flow together we are whole and healthy. The main principle in REIKI practice is that our life force nourishes the organs and cells and when it is blocked or disrupted, the body ceases to function well. Reiki practitioners facilitate the process of healing through the laying of hands on the body.

The universal energy enhances the flow of the person's energy or KI. "It offers many benefits," she added, "it helps to alleviate pain, it reduces fatigue, boosts immune system, and supports in processing emotional issues. It helps to ease the effects of different kinds of illnesses, both acute and chronic."

Karen Lazarus spoke about how massage benefited her mom during the time she was suffering from ALS. Karen describes massage as one the oldest forms of remedial therapy. Most modern methods of massage derive mainly from the Swedish. "It is an excellent way to relax the mind and body, and brings relief from every day stresses and strains. It also helps to restore a sense of calmness and balance after any shock or trauma," Karen said. There are different types of massage.

They are:

- Shiatsu- An ancient form of pressure point massage that is based on the principles of the Chinese discipline of acupuncture.
- Therapeutic massage- Consists mostly of soothing strokes and rubbing for the relief of pain or physical discomfort.
- Reflexology- Is a specialized massage for the hands and feet.
- Sports massage- Features a deep

tissue massage that aims to ease stiff joints, relax tense muscles and restore suppleness.

"Always remember hugs and smiles are the best treatment to keep you in contact with your family", said Karen.



"Aromatherapy is the use of essential oils from plants to enhance general health and appearance", said Eva Paglialonga. Aromatherapy is used for a wide variety of problems. The fragrance of an essential oil can directly affect everything from your emotional state to your lifespan. When a fragrance is inhaled, the odor molecules travel up the nose where they are trapped by olfactory membranes well protected by the lining inside the nose. Each odor molecule its like a little puzzle piece into specific receptor cell sites lining a membrane known as the olfactory epithelium. Each one of these hundreds of millions of nerve cells is replaced every 28 days. When stimulated by odor molecules, this lining of nerve cells triggers electrical impulses to the olfactory bulb in the brain. The sense of smell is the only one of the five senses directly linked to the limbic lobe of the brain, the emotional control center. Anxiety, depression, fears anger and joy all emanate from this region.

There are important guidelines to follow when using essential oils, especially if you are unfamiliar with the oils and their benefits.

- Keep bottles of essential oils tightly closed and store them in a cool location away from light.

- Keep essential oils out of the reach of children.

- Angelica, bergamot, grapefruit, lemon, orange, tangerine and other citrus oils are photosensitive and may cause a rash or dark pigmentation on skin if exposed to direct sunlight.

- People with high blood pressure should avoid using sage and rosemary.

- People with allergies should test a small amount of oil on an area of sensitive skin.

- Keep essential oils away from open flames, sparks or electricity. Some essential oils, including orange, white fir, pine and peppermint are potentially flammable.

Carina Wiklund, a physical therapist spoke about the roles of the physical therapy:

1. Assessment of what the patient can do, and their need for specific devices such as splints, braces, canes, walkers and wheelchairs.
2. Assessment of ADL's (Activities of Daily Living) needs and safety.
3. Development of a program of exercises. She said, that the therapy for the mind and body is a very important component to managing ALS symptoms.



CAREGIVER'S CORNER

By Karen Lazarus, RN

POWER OF TOUCH

Touch is one of the most infrequently used senses utilized now in our modern age times. We ask ourselves why is touch so infrequent? The answer is simple, we all want to give each other their "space." Yet, when a mother kisses the ache on a child's knee, the child believes that he/she is better. When a couple hold hands, they believe it's a connection between them. When we hold hands in prayer, we believe that the world will be saved and hope lives. When our loved ones are dying we hold them close and once they have passed to their next home, we dream only to touch them one more time. That is the power of touch.

Massage therapy is considered an alternative medicine. Before it was known as massage, it was called healing touch. Women more so than men cultivated this therapy over the years in different cultures, religions, and lifestyles. In our modern heritage, licensing and competency on a professional level is important to ensuring client care and well being. A professional massage therapist should listen to what the client's needs are and collaborate with their physician about these needs. Massage therapy is as dynamic as the client is. The balance will change according to the need of the client and their continuum of health.

Family members of ALS patients should understand this dynamic for they too will undergo changes, some slow and some faster than can be kept up with. Hugging, gentle touch, and the ability to kiss your loved ones are important. Even more important is the return of touch from them. It is their gift to you. Remember, you will later miss their physical presence, hugs and their touch.

Now we ask, what is massage therapy? For you it is the hug, kiss and the touch of the hands from the one you love most.

HUGGING

Hugging is healthy: It helps the body's immune system, it keeps you healthier, it cures depression, it reduces stress, it induces sleep, it's invigorating, it's rejuvenating, it has no unpleasant side effects and hugging is nothing less than a miracle drug.

Hugging is all-natural: It is organic, naturally sweet, no pesticides, no preservatives, no artificial ingredients and 100% wholesome.

Hugging is practically perfect: There are no movable parts, no batteries to wear out, no periodic checkups, low energy consumption, high energy yield, inflation-proof, non-fattening, no monthly payments, no insurance requirements, theft-proof, non-taxable, non-polluting and, of course, fully returnable.

Karen Lazarus

SAFETY CORNER

HURRICANE SEASON

South Florida's beautiful weather also brings with it tumultuous atmospheric conditions, better known as hurricane season. From June 1 through November 30, South Florida prepares for and anticipates the possibility of being affected by a hurricane. It will visit us every year, like an out-of state relative, and not bother us too much, hopefully. But if it does, you need to have a plan. Every year we give you information on what to do if a hurricane is headed your way and a disaster plan will be explained as follow:

- p If you live in an evacuation zone, make plans to move inland to a friend or family member's house.
- p If you live in a mobile home or are **ELECTRICALLY DEPENDENT**, you should evacuate to the closest hospital for any category of tropical storm or hurricane.
- p **Anyone needing assistance with their daily living including having electrically dependent medical equipment, should register for the EEAP (Emergency Evacuation Assistance Program) by calling the Office of Emergency Management at (305) 468-5900 TDD (305) 468-5402 to receive an application. Applications are available in Creole, English, and Spanish and can be downloaded from the OEM Website. <http://www.co.miami-dade.fl.us/oem>. When an application is turned into the office, the application should have all the information completed, including the doctor's signature. The key for this program is pre-registration, priority will be given to those who had the foresight to register ahead of time.**

BEFORE A HURRICANE COMES KNOCKING:

- **Check your insurance.** If you live in an area that could be affected by a hurricane's storm surge, make sure you have flood insurance.
- Prepare and take with you a box with your medical insurance papers, homeowner insurance papers, valuable papers, etc.
- Plan a meeting place. Make sure that everyone in your family knows where to meet, a relative's house for example, to prevent family members from becoming separated.

- Pick an emergency contact.
- Develop an emergency communication plan in case family members are separated. Ask an out of state relative or friend to serve as the family contact. Make sure everyone in the family knows how to reach the contact person.
- Be ready to evacuate your area. Be ready for it. Have your car gassed up and your disaster kit ready to go.

❖ EMERGENCY EVACUATION ASSISTANCE PROGRAM (EEAP)

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

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

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

Anyone who needs assistance with their daily living, including electrically dependent medical equipment should register. Contact us by e-mail or call directly at (305) 468-5900 - teammetro@miamidade.gov TDD (305) 468-5402 to receive an application.

❖ DURING A HURRICANE WATCH:

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

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

Team Metro Hotline:305 468-5900
 Haitian Support, Inc:800-443-2951

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

- ∇ State of Florida Emergency Information Line: ..800-342-3557
 TTY:800-226- 4329
- ∇ City of North Miami Beach305 919 0892
- ∇ City of Miami305 579-1800
- ∇ City of Miami-Beach305 673-7222
- ∇ Broward County954 831-4000
- ∇ Monroe County800-955-5504
- ∇ Palm Beach County407 233-3500

- Check your emergency supplies, turn your refrigerator and freezer to the coldest setting and open them only if necessary. Store drinking water in clean bathtubs and bottles.
- You should lock and board up windows, stow away small objects that could cause damage in high winds, remove outside antennas, and if you are going to ride the storm out elsewhere, turn the utilities off.

❖ DURING A HURRICANE WARNING

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

❖ WHEN EVACUATING BRING THE FOLLOWING ITEMS:

- ALL REQUIRED MEDICATIONS AND MEDICAL SUPPORT EQUIPMENT:
- Wheelchair/walker, oxygen, dressings, feeding equipment, diapers, etc.
- Any specific medication and instructions.
- Name, phone number of physician/home health agency/hospital where you receive care.
- SPECIAL DIETARY NEEDS: Only regular meals will be provided.

- REMEMBER: Pets are NOT allowed in Evacuation Centers. You must make other arrangements for them.
- People dependent on medical devices should make sure that they are in working order and that they have back up supplies for them.
- Have extra pairs of glasses and/or contact lenses.

❖ FOR ELDERLY AND DISABLED PATIENTS

- Plan on taking care of yourself without electricity. Remember that the person taking care of you and your electrical devices may not be available right before and directly after a storm. If you are not able to do so, make other arrangements now.
- If you are elderly, frail or a person with disabilities and have friends or relatives who can help with your property, housing and welfare, contact them now so that they can include your needs as part of their hurricane planning. They will need to include the time it will take for you to gather items you need and the transportation time.
- Make a list of prescribed medications and get a month supply. You should also make copies of the prescriptions. Your pharmacy's records may not be available right away.
- If you normally require a special diet, make sure you take along a three-day supply of it in containers that will be easy for you to open.
- Transfer to a manual wheelchair if you are in a battery operated one. You may not be able to recharge the batteries.
- Make sure you are wearing an ID bracelet with your name, medications, allergies, and contact information.
- If you are in a nursing home, ask to see their hurricane plan that details where and when the residents will be evacuated. Be sure to let your family or friends know where you will be taken if evacuated.



MY BOOK OF RECIPES

Noodle Kugel

Ingredients

8 oz. Cream cheese
 1 1/2 cup sugar
 6 eggs
 2 cups milk
 2 cups orange juice/or apricot
 1 lb. wide noodles
 1 1/2 sticks margarine

3 cups cornflakes
 1 stick margarine

1. Cook noodles according to package directions.
2. Mix all together and pour in 9 x 13 baking dish.
3. Crush the cornflakes and mix with melted margarine.
4. Sprinkle over the top of the noodles.
5. Bake in 350° oven for 45 minutes

Chocolate Frosting

3 cups powdered sugar
 2 oz. bitter chocolate squares
 1/3 cup milk
 2 tsp vanilla
 1/4 cup margarine

1. Melt margarine and chocolate squares in microwave. Be careful not to burn the chocolate.
2. Add powdered sugar, vanilla and milk to spreading consistency.



PATIENT TALK

A Page in Ed White's Journal An E-mail Conversation Between Ed White & Dr. Walter Bradley

Part 1

Ed White: COMPETITION: Like most ALS patients, I have been in competition with something all my life. It started with high school athletics; carried through into a very competitive business environment; and I even competed with myself in numerous marathons. Now I find myself competing with ALS. Initially I thought this was unhealthy, but now I do not feel that way. It has always

been my nature to compete, so why not carry through and direct this competitiveness toward ALS. I have certainly had enough experience in this area and I find it pays dividends with ALS. In my opinion, competition with ALS is beneficial; why not use it to one's advantage?

HEALTH MAINTENANCE: For the ALS patient, it is very important to treat

the total package. In other words, one should maintain all aspects of health in addition to addressing ALS. Psychologically, this is very important. ALS is local. By that I mean it cannot be treated on a long distance basis; there are just too many day-to-day, in-home issues to consider. This also includes other aspects of the patient's over-all health.

So, it is important to find local doctors and dentists who are understanding and willing to work with you. In instances where the reputation of ALS has preceded you, and a doctor shows limited understanding, or his eyes glaze over when you talk to him, simply move on and find another doctor. They are out there and can be invaluable to the patient whether dealing with ALS-related problems, or other health issues. If ALS patients expects to live with ALS long-term, they must maintain all aspects of their health, and not just focus on ALS alone.

CENTIMETERS: I have often said that ALS is a disease of centimeters. By that I mean, when I ask for some movement, it is never more than a few centimeters, whether it is my position in the wheelchair, position in bed, position of my mask, position of my sip and puff, and so on. Movement is never more than a few centimeters. One of the first things I try to emphasize with my caregivers is to think in terms of centimeters; ALS is a disease of centimeters.

FINANCIAL: Living with ALS on a long-term basis can be one of the most expensive diseases to deal with. Expenses cover the gamut from respiratory equipment to caregivers to drugs and supplements, and so on. The interesting thing that has struck me over the years in communicating with patients is the variation in expense levels. Some who are quads with trachs spend relatively little. This, of course, puts a heavy demand on family and friends. Others I have spoken with are spending over \$100,000 a year for equipment, caregivers, and medications. Most patients fall somewhere in between.

Medicare can be of assistance on some of the necessary equipment. Unfortunately, there is no help there when it comes to outside caregivers and nurse assistants. Hopefully, the efforts made here by David Jayne and others will change Medicare's approach to ALS patients who are homebound.

In summary, ALS requires a certain financial minimum for survival. But, I have talked with so many patients who have demonstrated to me, although difficult, that where there is a will, there is a way. And where there is a strong will to survive, they somehow pull the resources together to make this possible.

Dr. Bradley: I AGREE. OUR FIGURES INDICATE THAT AT YOUR STAGE, THE COST IN DIRECT EXPENSES (FORGET ABOUT LOST EARNINGS FOR YOU AND YOUR CAREGIVER) IS ABOUT \$100,000/YEAR. FOR SOMEONE ON A VENTILATOR THE COST CAN RUN FROM \$250,000 TO \$500,000/YEAR!

Ed White: CAREGIVERS: Because of the debilitating nature of ALS, good caregivers are an absolute necessity for living with the disease. I am fortunate in that my wife, Linda, is a wonderful caregiver and serves as the focal point for my care. I am also fortunate to have good Home Care nurses who have been with me for years and come to my home every day. I know this can be a problem as many patients continue to battle the turnover with outside caregivers. From my experience in talking with patients over the years, the inability to find good caregivers is second only to the inability to establish a good respiratory management program.

This is a serious problem, and unfortunately, is getting worse.

Dr. Bradley: AGAIN, I AGREE WHOLEHEARTEDLY. THE CAREGIVER'S BURDEN IS SOMETHING THAT THE ALS CENTERS AND COMMUNITY ARE ONLY JUST BEGINNING TO GET A HANDLE ON. THERE IS A "SCALE" FOR MEASURING THIS IN THE ALS CARE DATABASE, AND THE STRIKING THING IS THAT THE MEASURE SEEMS TO STAY FAIRLY CONSTANT THROUGHOUT THE DEVELOPMENT OF THE DISEASE. IT SEEMS TO ME THAT THE PHYSICAL AND EMOTIONAL BURDEN INEVITABLY INCREASES WITH TIME, BUT EITHER CAREGIVERS FIND THE EMOTIONAL PAYBACK OF "GIVING" COUNTER-BALANCES THIS, OR THEY SIMPLY CANNOT ADMIT TO HOW MUCH OF A BURDEN IT REALLY IS. CAREGIVER BURNOUT IS A REAL PROBLEM; I HAVE SEEN MARRIAGES AND RELATIONSHIPS BREAK UP OVER THIS, AND IT IS NOT SURPRISING. I ALWAYS TRY TO GIVE ATTENTION TO THE CAREGIVER, WHENEVER I SEE A PATIENT. I TELL BOTH THE PATIENT AND THE CAREGIVER THAT THE LATTER IS JUST AS IMPORTANT, BECAUSE IF THEY FAIL, THEN THE PATIENT WILL HAVE TO BE ADMITTED TO THE HOSPITAL FOR CARE.

CONCERNING THE PROBLEM OF FINDING GOOD NURSING AND HOME HEALTH AIDS, WE HAVE BUILT UP A CADRE OF PEOPLE AND HOME HEALTH SERVICES WHO ARE EXPERIENCED IN CARING FOR ALS PATIENTS. WE ARE LUCKY ENOUGH TO HAVE TWO FUNDS FROM WHICH WE CAN HELP PAY FOR THESE AGENCIES. THIS IS SOMETHING THAT THE WELL-ESTABLISHED ALS CENTER CAN DEVELOP.

RESEARCH CORNER

**Clinical Trials Update - From ALSA's National Office****FOR IMMEDIATE RELEASE**

June 10, 2003

Contact: alsinfo@alsa-national.org

Toll Free (800) 782-4747

Enrollment to Begin for ALSA Co-sponsored Clinical Trial of Myotrophin in ALS

After some delay, the Phase III multi-center clinical trial of Insulin-like growth factor (IGF-1), Myotrophin™ is about to start. Patient enrollment begins this month at five of the study sites. These sites include the certified ALSA Centers at the Mayo Clinic in Rochester, Minn., the Mayo Clinic in Scottsdale, Ariz. and at the Hennepin Faculty Associates in Minneapolis, Minn. Other sites to begin enrollment this month are the University of Cincinnati and the Mayo Clinic in Jacksonville, Fla.

The certified ALSA Center at the University of Michigan, Ann Arbor, Mich., and the Henry Ford Hospital in Detroit, Mich. are finalizing plans to begin accepting patients into the study later this summer. Also planning to begin enrollment this summer is the Medical College of Wisconsin in Milwaukee, Wisc.

Other sites will be ready to enroll patients into this study once staff training has been completed later this year. ALSA's web site includes a full listing of all of the Myotrophin study sites and the contact information for each site. http://www.alsa.org/news/news012302_2.cfm. For information about enrolling in this study, contact the study sites.

The objective of this trial is to determine whether IGF-1 (Myotrophin™) slows the progression of weakness in amyotrophic lateral sclerosis (ALS). Three hundred patients with ALS from multiple medical centers will participate in this double blind, placebo-controlled two-year study.

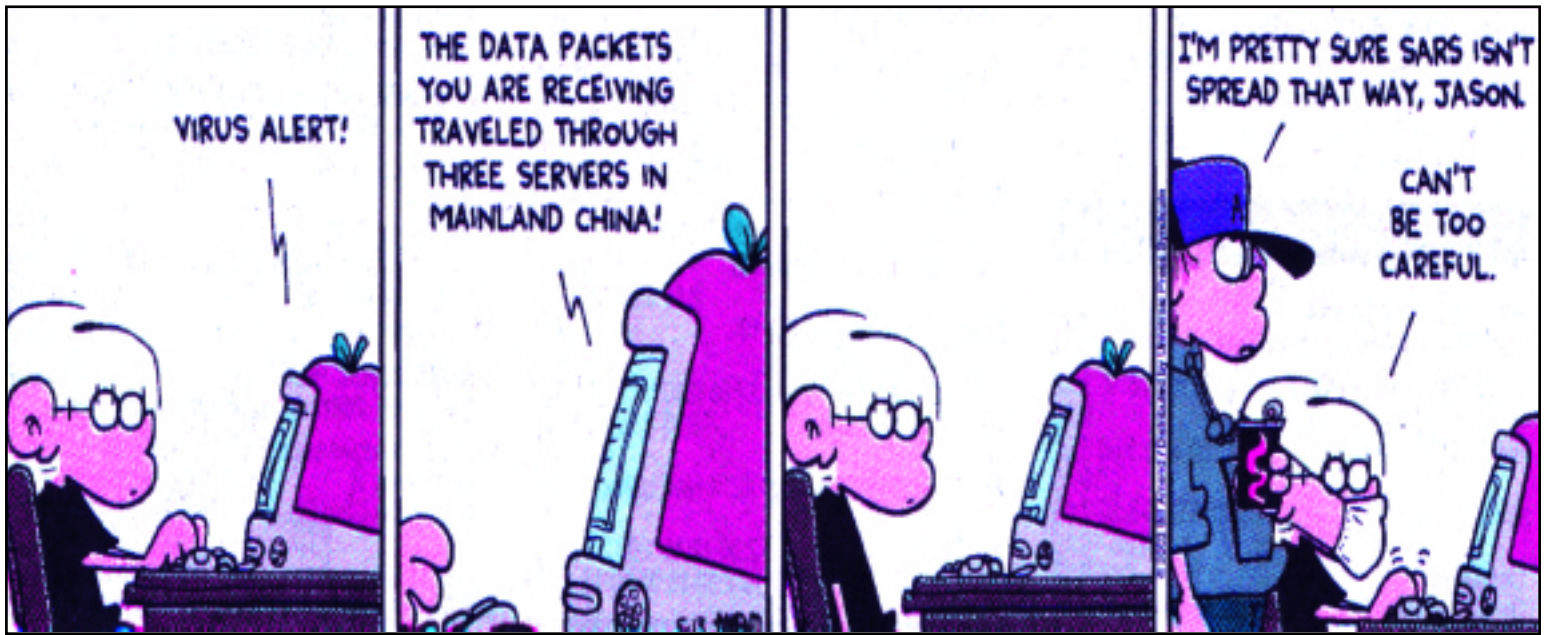
If conclusive, the results of this study will be an important factor in a decision to approve this medication for general use in ALS. The National Institute of Neurological Disorders and Stroke (NINDS) and The ALS Association (ALSA) are funding the study.

Previous clinical trials of IGF-1 in ALS patients in the U.S. and in Europe have led to conflicting conclusions (positive results in U.S. and negative results in Europe), most likely due to differences in study design. In these clinical trials there were no significant drug-related adverse events, other than mild injection site irritation. Continued laboratory work with IGF-1 and strong patient and family interest have led to this new clinical trial.

For further information about the IGF-1 trial, including answers to frequently asked questions (FAQs) and a list of the study sites, visit ALSA's web site at <http://www.alsa.org/news/news012302.cfm#SUMMARY> and contact one of the individual [study sites](#) or call ALSA at (800) 782-4747.

For more information about ALS and the work of The ALS Association, please visit www.alsa.org.

The ALS Association is the only national not-for-profit voluntary health organization dedicated solely to the fight against ALS. Its mission is to find a cure for and improve living with ALS.



IMPORTANT NUMBERS

- Kessenich Family MDA ALS Center305-243-7400
-1-800-690-ALS1
-www.miami-als.org
- Muscular Dystrophy Association (National Patient Information)1-800-572-1717
-www.mdausa.org
- St. Petersburg717-576-5202 or 1-800-393-8552
- Palm Beach Gardens561-242-5084 or 1-800-289-0535
- Miami305-717-9937 or 1-800-572-0085
- Broward(954) 757-4357 or 877-970-9696
- ALS Association1-800-782-4747
- ALS Association in Florida1-888-257-1717
-www.alsa.org
- National Caregiving Fdn1-800-930-1357
- National Family Caregivers Assn1-800-896-3650
-www.nfcares.org
- Foundation for Hospice and Homecare202-547-6586
- 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 Online1-800-772-1213
-www.ssa.gov
- The Feeding Gastrostomy Information:www.iinet.net.au/~scarffam/gtube.html

- ALS Digest (Bob Broedel): To subscribe, please e-mail tobro@huey.met.fsu.edu

If you need a referral to see 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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• Support Group Dates

Saturday, August 9, 2003
“ September 13, 2003
“ November 8, 2003
“ December 13, 2003

Location: University of Miami
Hospitals & Clinics
1475 NW 12th Avenue
Room 1301
12:00 - 1:30 pm

• Support Group for Caregivers only

Saturday, July 12, 2003
“ October 11, 2003