

The Kessenich Family MDA ALS Center

*Celebrate...the tradition of
Friendship, the beauty of the season, and a
New Year of Peace and Happiness*

*Merry Christmas
Feliz Navidad
Happy Hanukka*

*From all of us at the Kessenich Family MDA ALS
Center*



Please greet our new staff in the Kessenich Family MDAALS Center and Multiple Disciplinary Team



**MARY ELLEN
KAYATA, M.S.,
CCC-SLP**

Mary has been a Speech-Language Pathologist for 13 years, and has been working at Jackson Memorial Hospital for the past 7 years evaluating and providing treatment to both adults and pediatric population with various neurogenic

diagnoses. Mary joined the Kessenich ALS clinic to provide education, treatment with regards to speech and swallowing problems as well as augmentative communication information as necessary.



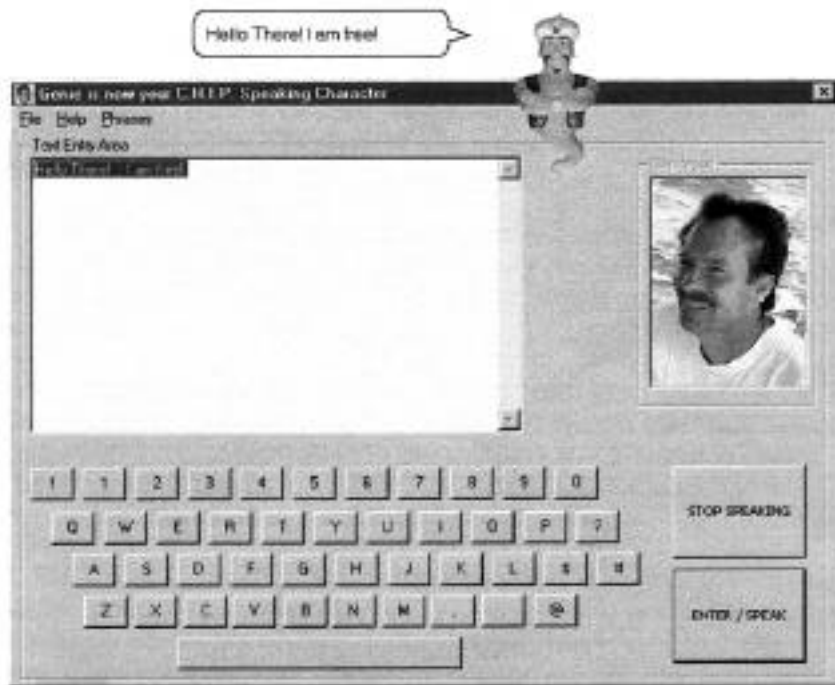
LAURA M. MAIO

Laura is a medical transcriptionist who graduated from National School of Technology.

She has two years of transcription experience in most fields of medicine and specializes in neurology and surgery. She joined the Kessenich Family MDAALS Center as a Sr. Staff Assistant, and she assist with the preparation and execution of several fundraising projects. She also aids with administrative duties and serves as support staff for the clinic and the ALS support group.

Welcome Laura and Mary Ellen

Patient Corner



CHIPSpeaking™

CHIPSpeaking™ stands for: Conversational Help for the Individuals with Problems Speaking.

My brother George McF. Mood, III, P.A. is a pretty darned good guy. He enjoys gardening and computers. He also has ALS. His speech has been affected by the disease, along with part of his motor skills he can, with great effort, use his arms, but fine motor skills are exceptionally difficult for him. He is known as Chip since he was a chip off the old block, according to our parents.

I named this software after my brother Chip (picture above) who has been losing the capacity to speak due to ALS (Amyotrophic Lateral Sclerosis or Motor Neuron Disease) commonly known as Lou Gehrig's Disease, after the great baseball player.

When my brother George McFarlane Mood, III was diagnosed with ALS, he was beginning to speak poorly, but could be understood. In the space of the last two years, it has become more and more difficult for him to be understood.

Chip asked me while ago to seek out speech synthesizer software. I found that 'name brand' program ran \$800.00 and up for the software. Some of

these programs require additional proprietary software to work. The cheapest I found was a total of almost \$2,000.00. I see that as an affront to the humanity of the victims of this and other diseases that steal vocal abilities. To be robbed twice would be heartbreaking. I am determined to keep this software free for many reasons, but mostly because I have seen firsthand the anguish felt by ALS victims.

So I decided to write some software using the text to speech software that Microsoft supplies for free. We're on the right track with free. Next I had to get the Agent™ software from Microsoft. Thanks Bill and Co.!

So then came the fun part. Writing the software. It took about three weeks of fiddling with Visual Basic™ until I re-learned BASIC within the Windows environment. Once I got the hang of it, it took quite a number of hours programming and testing time to come up with a test version.

It's simple, and quite easily used. The buttons are easy and fairly large to accommodate persons with motor skill difficulties. It also has an area to type what you want the computer to say. It also can let you paste text into the speech entry area. This allow you to read your e-mail without looking at it, which will allow persons with difficulty seeing

small text on the screen to hear their messages.

The software requires a multimedia equipped IBM™ or compatible computer. In short, it is a pure 32 bit program, and even though you may have Windows 3.1 operating system, you don't have enough hardware to run this. Windows 95 and up can run it without any problems. It has been tested under Windows 95, Windows 98 (Revision 1 and 2) and Windows NT. I have been unable to test with Windows 2000, but all the indicators are that it will run in a Windows 2000 environment. (Anyone who tries it on any platform, especially Windows 2000 and has troubles, make notes of error messages and any other programs running concurrently if problems occur and let me know please). I could use the help, and so could our vocally disabled friends and relatives. Even someone with laryngitis can use this program for free. ANYONE can use it. Some of my co-workers enjoy it because they can read their mail with it and work with their hands on other projects while they listen to the mail.

To get a copy, you can either download the files from this site: http://members.xoom.com/_XOOM/chipspeaking/index.htm or get a CD from me by mail. The files total about 5.6 megabytes, and should take only a few minutes with a 56K modem. It may stretch your patience to the limit to try to download this with any modem slower than 33.6. There are four parts, and each must be installed in your computer before CHIPSpeaking™ will work. All four are linked to:

http://members.xoom.com/_XOOM/chipspeaking/index.htm

CHIPSpeaking™ is a software product that is FREE for anyone, so long as no commercial purpose is served and no fee is charged for its use. The program starts out with a gray text entry screen. This will change its color once you have opened the File/Open dialog. Then you pick a person (character file). Once you have done this, you can see the white text entry screen. Just type, and when you hit the ENTER or RETURN key, it will process your words into speech and the character's lips will move and animate its expressions. Speech comes out of the sound card and speakers, hence the requirements of multimedia equipped computer. Please check the Help menu and look over the information there. If

you need help with the program, feel free to send me an e-mail with the details of the problem. I will get back to you as soon as possible. If it requires phone support, I may have to call you collect, but I will call. Just state a good time during the evening and I will call the number you leave collect. Have your notes handy so we can get to the heart of your problem fast.

ALS patients, as well as those who have lost the ability to speak for whatever reason will benefit from your support of this software. Your support can take several forms.

First, you could send me some supplies (CD's mostly are needed to publish this program) to help me defray the cost of sending CD's and diskettes to people who need the program. I have several contacts in the medical community who are trying to help spread the world of this program. I want to keep this program completely free and with your help I can. Donations of any kind are completely voluntary. The program is and always will be free. Anything you send that is surplus will be sent to the University of Miami ALS Research Foundation and you will be credited with it.

My Address is:

John T McF. Mood, Sr., S.F.O.

3723 Ashley Hall Dr.

Charlotte, NC 28227-5502

Second, you could send out to the University of Miami A.L.S. Research Foundation (or the short form: U. of M. A.L.S. Research Foundation.) I will forward it, and your donation will be credited to you. An acknowledgement will be sent to you for tax purposes. Remember, your donation is voluntary, The program is free WITHOUT any donation.

Lastly, you can download the MakeCD.zip file and burn a CD for a person in need of it. It's cheap when you consider the costs to the people who cannot speak for themselves!

My Book of Recipes

Salmon Quiche

- 1/2 onion, finely chopped
2 5.33 ounce cans evaporated milk

- 4 eggs, beaten
1 large can salmon
2 cups grated cheese
1 unbaked pie shell
butter
salt and pepper to taste

Saute onion in butter in skillet. Add evaporated milk, eggs, salmon, cheese, salt and pepper, mixing well. Pour into pie shell and bake at 375 degrees for 40 minutes. Makes 6 servings.

Nutritional Analysis Per Serving:

Calories559.00 Protein33.67 g

Rice Pudding

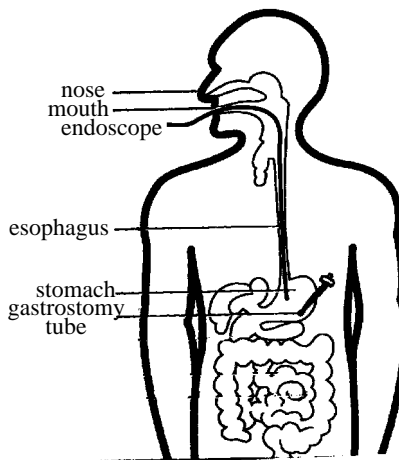
- 1 tablespoon cornstarch
2 1/2 tablespoon honey
1 egg, beaten
1 cup milk
1/2 cup rice, well cooked
1/2 teaspoon vanilla

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

Nutritional Analysis Per Serving:

Calories110.75 Protein3.75 g

Tube Feeding at Home



It is far better to make the choice as early as possible, before weight loss effects the muscle tone of the respiratory system. The stronger you are, the more easily the procedure for inserting the tube becomes and the quicker you can adjust to the tube

after surgery.

PEG Tube

The percutaneous endoscopic gastrostomy (PEG) tube is currently used most often. The tube is approximately 10 inches long. A large endoscope (instrument) is passed through an opening in the abdominal wall. One of the greatest advantages of this method is that usually no general anesthesia is needed, only heavy sedation. With a skilled physician and a nurse, this procedure can be done quickly with few problems. You may be able to go home the same day. Problems with initial feedings can be dealt with by experienced personnel while in the hospital.

It is important that patients and caregivers feel knowledgeable and confident before going home. Arrangements can be made for visits by home care nurses until you feel confident.

Liquid medications rather than crushed pills are preferred through a PEG. Bulk-forming agents such as Metamucil, should not be given through a PEG tube. Blenderized foods may be used if they are able to pass through the eyelets at the end of the tube. Have your doctor show you a tube before he inserts it. Careful routine flushing with water is a necessity to keep it from clogging.

Basics of Tube Feeding

The more you know about tube feeding, the more comfortable you will be. Following are questions most often asked about tube feeding:

Why is tube feeding necessary?

People are tube fed because they can't eat enough regular food to get the necessary nutrition and fluid they need.

Do liquid medical nutritional products have all the nutrients I need?

Yes. When given in the right amounts, these products contain all the nutrients needed, the same as you would get from a well-balanced diet of regular food-protein, carbohydrate, fat, vitamins and minerals.

What are the nutritional needs of a person being tube fed?

Everyone's needs differ, so your nutritional needs will be identified by

your health care professional.

Can I eat through my mouth after PEG insertion?

Yes. You can still eat through your mouth until your are not able to do so. Consult with your physician about this.

For Family and Friends

As a family member or friend, your support can make all the difference. Encourage the person being tube fed to discuss their feelings about tube feeding. Sometimes family members feel guilty about eating in front of tube-fed patients. Some tube-fed persons still enjoy being with family and friends at meals; others may not. Talking openly about these concerns can help you decide how the family can take pleasure in being together.

Preparing the Medical Nutritional Products

Medical nutritional products comes in two forms: Powder and Ready to Use in cans and bottles. Your health care professional will tell you which one to use.

Preparing any nutritional product begins with washing your hands well with soap and warm water and rinsing thoroughly.

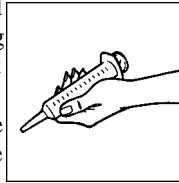
To fix canned or bottled Ready-To-Use Product:

- 1.-Shake the can or bottle well.
- 2.-Wipe the top of the container with a clean cloth before opening.
- 3.-Cover any unused open product and store it in the refrigerator.
- 4.-Write the date and time on the opened container. If not used within 48 hours, throw it away.

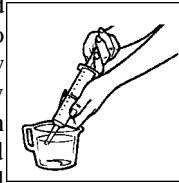
Getting Ready

- 1.-Wash your hands well with soap and warm water and rinse thoroughly.
- 2.-Gather all equipment
 - Nutritional product
 - 30 ml to 60 ml syringe
- 3.-Use a measuring cup to measure the amount of nutritional product needed. Cover unused product and refrigerate. Write day and time on container as previously instructed.
- 4.-To give water or other fluid by syringe method:

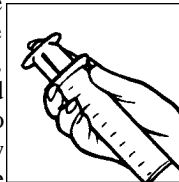
- Gather all equipment, including nutritional product and large syringe.
- Remove the plunger from the syringe.



- Place the tip of the syringe into the feeding tube.
- Pour the prescribed amount of water into the syringe and allow it to flow in by gravity; then pour in the prescribed amount of nutritional product and allow it to flow in slowly.



- After all the products has gone through the tube, pour the prescribed amount of water into the syringe and allow it to flow into the tube. There are several positions that are safe and comfortable for tube feeding:



- Sitting up in a chair.
- Propped up in bed or on a couch in a half sitting position (with head raised 30° or more).

To prevent vomiting, never lie flat during your feeding or for 1 hour afterward...or permit someone you are feeding to lie flat. Vomiting or coughing up small amounts of fluids can lead to breathing fluids into the lungs (aspiration). Aspiration is dangerous. If coughing or choking starts or breathing becomes difficult. STOP THE FEEDING IMMEDIATELY and call your healthcare professional.

To Check Residual

Only those fed through a G-tube should have a residual.

After you have injected air into the G-tube and heard a “bubbling” sound, check the residual in this way:

- 1.-Gently draw back the plunger of the syringe to withdraw stomach contents. **(You may not obtain any residual if the stomach is empty or if the tube is placed in the duodenum or jejunum rather than the stomach.)**
- 2.-Check the amount in the syringe.
- 3.-Inject the contents back into the feeding tube.

4. After reinjecting the residual, use the syringe to rinse the feeding tube with 20 to 30 ml. of warm water.

If the gastric residual is more than 100 ml. or 2 times the hourly feeding rate, or you cannot obtain residual but the person being fed feels unusually full or nauseated, wait 30 to 60 minutes and do another residual check. If the gastric residual is still high or cannot be obtained, DO NOT give the feeding. Contact your health care professional for instructions so that the feeding may be restarted as soon as possible.

Cleaning the Stoma Site

Until the Stoma site heals, follow these steps to clean the skin around the stoma:

- 1.- Gather all materials you need: bottle of hydrogen peroxide, gauze squares, 2 clean containers - one for the hydrogen peroxide mixture and one for the rinse water, and cotton swabs.
- 2.- Pour equal amounts of hydrogen peroxide and warm (not hot) tap water into a clean container.
- 3.- Pour warm tap water for rinsing into another clean container.
- 4.- Pour the hydrogen peroxide mixture onto a gauze square to clean carefully around the tube.
- 5.- Work in widening circles, beginning next to the stoma site.
- 6.- If the tube has a disk next to the skin, use a cotton-tipped swab to clean under the disk. Be careful not to pull at the tube.
- 7.- Use a gauze square with warm (but not hot) water to rinse the skin.
- 8.- Allow the area to dry.
- 9.- If prescribed by a doctor, a small amount of medicated ointment should be put on the skin around the tube.

After the stoma site heals, you do not need hydrogen peroxide. Follow steps 5 through 9 above using a clean cloth with mild soap and water to wash the skin. *(Gauze is not necessary in step 7...a clean washcloth is fine)*

Observe the stoma site closely every day. Watch for any of these signs:

- Redness
- Swelling
- Pain or soreness
- Unusual drainage around the tube

If you notice any of these symptoms, call your health care professional as soon as possible.



Caring for the Mouth

Good mouth care is very important even when you're not eating or drinking. Brush all surfaces of the teeth, gums and tongue at least twice a day, using a regular toothbrush and toothpaste. Use a mouthwash as needed. If your mouth becomes dry, ask your health care professional if it is okay to chew sugar-free gum or suck on sugar-free mints or candies.

If your PEG is out of place, call your physician and go to the emergency room as soon as possible the hole will close in 24 hours and they can re-insert a new PEG again in few minutes.

Patient talk

Staying in the Now

By Cindy Silverman with Debbie Kasper

I was diagnosed with ALS two very long years ago. It has been an emotional, spiritual and physical roller coaster ride since then. I have learned to savor the smiles of the high points on this ride, because I know I'm going to inevitably hit the low points. But if I can remember the roller coaster image when I'm feeling low, it will help me keep my momentum going, and let me rebound faster. This is the

only way I know of to avoid feeling overwhelmed by this illness.

As my deterioration has progressed, I have tried to use my time to make room for the mundane as well as the gargantuan changes in my life. Each day shows me how my way in the world has changed. We are all given the time to adjust to changes, if we choose to take it. It seems to me, no coincidence, that it takes nine months for a baby to grow, giving the expectant parents all that needed time to get used to the idea of the changes to come.

I'm sitting here in a motorized wheelchair, which was greatly improved my quality of life, and I'm very thankful for it. But if a year ago, I could've looked into the future and seen myself in this wheelchair, I would've been eaten away by anxiety and sadness. Today, this wheelchair is the best tool I have to help overcome my handicap.

When I look towards the future, I am filled with fear. If I stay in the present, then I realize that I am perfectly safe. This is my "now" and it's up to me what I choose to do with it.

Caregiver's Corner

November 1999 National Family Caregivers Month

November is National Family Caregivers Month (NFC Month). This is a great time to honor and assist the over 25 million Americans who do so much to help others, but receive little recognition and support themselves. We encourage you to reach out to family caregivers all during the month of November. If you are not a member of the National Family Caregivers Association (NFCA), we urge you to join and support our efforts in behalf of caregivers during the whole year.

To learn more about NFC Month and to receive updates and order forms for materials, contact:

National Family Caregivers Association
10605 Concord Street, Suite 501
Kensington, MD 20895-2504
1 (800) 896-3650
E-mail: info@nfcacares.org
Website: www.nfcacares.org

INSTRUCTIONS FOR LIFE

1. Give people more than they expect and do it cheerfully.
2. Memorize your favorite poem.
3. Don't believe all you hear, spend all you have or sleep all you want.
4. When you say "I love you", mean it.
5. When you say "I'm sorry", look the person in the eye.
6. Be engaged at least six months before you get married.
7. Believe in love at first sight.
8. Never laugh at anyone's dreams. People who don't have dreams don't have much.
9. Love deeply and passionately. You might get hurt but it's the only way to live life completely.
10. In disagreements, fight fairly. No name calling.
11. Don't judge people by their relatives.
12. Talk slowly but think quickly.
13. When someone asks you a question you don't want to answer, smile and ask "Why do you want to know?"
14. Remember that great love and great achievements involve great risk.
15. Call your mom.
16. Say "bless you" when you hear someone sneeze.
17. When you lose, don't lose the lesson.
18. Remember the three R's: Respect for self; Respect for other; Responsibility for all your actions.
19. Don't let a little dispute injure a great friendship.
20. When you realize you've made a mistake, take immediate steps to correct it.
21. Smile when picking up the phone. The caller will hear it in your voice.
22. Marry a man/woman you love to talk to. As you get older their conversational skills will be as important as any other.
23. Spend some time alone.
24. Open your arms to change, but don't let go of your values.
25. Remember that silence is sometimes the best answer.
26. Read more books and watch less TV.
27. Live a good, honorable, life. Then when you get older and think back, you'll get to enjoy it a second time.
28. Trust in God but lock your car.

29. A loving atmosphere in your home is so important. Do all you can to create a tranquil harmonious home.
30. In disagreements with loved ones, deal with the current situation. Don't bring up the past.
31. Read between the lines.
32. Share your knowledge. It's a way to achieve immortality.
33. Be gentle with the earth.
34. Pray. There's immeasurable power in it.
35. Never interrupt when you are being flattered.
36. Mind your own business.
37. Don't trust a man/woman who doesn't close his/her eyes when you kiss.
38. Once a year, go someplace you've never been before.
39. If you make a lot of money, put it to use helping others while you are living. That is wealth's greatest satisfaction.
40. Remember that not getting what you want is sometimes a stroke of luck.
41. Learn the rules, then break some.
42. Remember that the best relationship is one where your love for each other is greater than your need for each other.
43. Judge your success by what you had to give up in order to get it.
44. Remember that your character is your destiny.
45. Approach love and cooking with reckless abandon.

Research Corner

Gabapentin (Neurontin) Anticonvulsant Drug Proves Ineffective for ALS

Gabapentin, manufactured by Parke-Davis, a division of Warner-Lambert (Morris Plains, N.J.) is already on the market for the treatment of epilepsy. A study published in December 1996 issue of *Neurology* suggested it might have some benefit in ALS and that further study was warranted.

Patients with classical, sporadic ALS were enrolled in an open-label study to investigate the efficacy of gabapentin in the treatment of ALS. The efficacy outcome is disease progression,

measured by the rate of change in the total score of the Appel ALS rating scale (AALS). Patients were evaluated every three to four months and their AALS total score was recorded at each visit.

Gabapentin is a synthetic compound structurally similar to the neurotransmitter gamma-aminobutyric acid (GABA), but its properties are different. In experimental studies, gabapentin has demonstrated a neuroprotective effect on rat motor neurons against glutamate-mediated toxicity. By analogy, gabapentin may slow progression of disease or prolong survival in patients with ALS.

However, a recent multi-center trial involving more than 200 patients at 13 centers throughout the country, **Phase III trials of efficacy of gabapentin in improving muscle strength and coordination in patients with amyotrophic lateral sclerosis (ALS) did not show the drug to be effective.**

The final result was presented October, 1999 at the annual meeting of the American Neurological Association, the trial showed no difference between those on active treatment and those on placebo in terms of muscle strength, ability to function in daily life or breathing capacity.

Dr. Robert Miller, Director of MDA's ALS Center at California Pacific Medical Center in San Francisco, and the coordinator of the study acknowledged that he was "crushed" by the failure of the drug to improve any aspect of the patient's disease. "We have one drug, riluzole, or Rilutek, and it is FDA-approved because it prolongs survival in ALS. We were hoping that this was going to be drug number two."

He also pointed out that one other drug currently being tested in ALS patients is the antiepilepsy topiramate, which like gabapentin, blocks glutamate activity. It will take "at least a year" to determine whether topiramate will be of benefit to patients with ALS.

Information obtained from Reuters News, Baylor College of Medicine and MDA Association.

Safety Corner

Plan Ahead for the New Century

Health and Medical

- Have several days to a week's supply of prescription and non prescription drugs available.
- Check with manufacturer company about medical equipment Y2K compliance. Refer to volume 1 issue 5 about year 2000 products compliance
- Learn basic first aid, and have a first aid kit handy.
- Keep paper records of your medical history.

Food and Water

- If electric service fails, first use perishable foods from your refrigerator. Then use foods from the freezer. (In a well-filled, well-insulated freezer, food usually will have ice crystals in the center - indicating it is safe to eat - for about three days.) Finally, use nonperishable foods.
- Purchase food items in container sizes that will be used entirely when first opened.
- Have a manual can opener and disposable plates and utensils available.
- Stock supplies to last several days to a week for each member of your family. This includes a variety of nutritional, nonperishable foods.
- Store a minimum of one gallon of water per person, per day, for each person in your household for a one-week supply. That's two quarts for drinking and two quarts for food preparation.
- If you have pets, have a supply of nonperishable food, water and their medications available.

Cash and Financial Resources

- Have at least one or two week's worth of cash on hand.
- Don't depend on automated teller machines (ATMs) for extra cash.

- If you receive a credit card with a year 2000 expiration date, carry your checkbook or some cash in case you encounter a noncompliant terminal.
- If possible, make your mortgage and car payments early or one month ahead.

Power and Fuel

- Plan on filling your vehicle's gas tank before Dec. 31.
- Fill your home heating oil tank, too.
- In case your power fails, plan to use alternative cooking devices - but only according to the manufacturer's instructions. Don't use open flames or charcoal grills indoors.
- If you plan to use a portable generator, follow the manufacturer's instructions. Keep it in a well-ventilated area, either outside or in your garage with its outside door open.
- If electric heat is unavailable, a fireplace, wood stove or free-standing kerosene or propane heater may be used.
- Do not use gas-fueled appliances, such as an oven, as an alternative heating source. Camp stoves and heaters should only be used outdoors. If you do purchase an alternative heating device, make sure it is approved for indoor use and is listed with the Underwriters Laboratories (UL).
- Have blankets, coats, hats and gloves available, January can be cold, particularly in North Florida.
- Have plenty of flashlights and extra batteries available. Do not use candles for emergency lighting.
- If you have smoke alarms that are hard-wired into your home's electrical system, check to see if they have battery backups, and install new batteries.
- If there should be a prolonged power outage, be prepared to relocate to a shelter. Listen to a battery-powered radio for shelter information.

Transportation

- Malfunctions could occur with traffic signaling devices, so it is advisable to stay off the road at midnight Dec. 31.
- Because of the immense number of computer systems that support public

transportation, some experts speculate that airlines will reduce or cancel flights on Dec. 31 and Jan. 1 in order to be safe. You might want to plan trips for the middle of December or January. If you must travel on New Year's Eve or Day, check with your airline.



Events

Second Annual Education Day

The Kessenich Family MDA ALS Center of the University of Miami will be holding their 2nd Annual Education Day on Saturday, February 5, 2000, from 12:00 m. until 4:00 p.m. at the University of Miami, George A. Smathers Student Wellness Center, located at 1241 Dickinson Drive in Coral Gables. More than 20 companies will be giving out information about new equipment, Social Security, Communication devices and much more. We look forward to your participation at this event. For more information, call Ginna Gonzalez or Graciela Reyes (305) 243-7400

Golf Tournament

The 2000 Golf Tournament will be held on February 26, 2000 at Golf Club of Miami. Please contact person: Tod Roy (305) 884-2352 or José Pérez: (305) 271-9502.

Jose A. Perez, patient and president of the UM ALS Research Foundation, is the driving force behind this fourth annual event. Jose's mission is to raise awareness and funds to find the cause and cure for this insidious disease. Your presence is going to make the difference, come and join us in this day, full of fun and surprises.

Other Announcements

THE CAMPAIGN FOR JUSTICE

Equal Justice for People in Poverty
Legal Services of Grater Miami, Inc. help people in
Dade County who have a household income
below 125% of the federal poverty guidelines.
We do not charge a fee for our legal services.

Main Office 3000 Biscayne Boulevard Suite 500
Miami, Florida 33137
Telephone (305) 576-0080
TDD (305) 573-1578
Carolina Lombardi, Directing Attorney
Intake hours-Monday through Friday
9:15 a.m. - 11:30 a.m. / 1:15 p.m. - 4:00 p.m.



You are invited our Thanksgiving luncheon

on November 20, 1999,
at University of Miami Hospital and Clinics, room 1537
from 12:00 p - 1:30 p

Please join us for the Holidays Celebration Luncheon

On December 11, 1999, at
University of Miami Hospital
and Clinics, room 1537
from 12:00 p - 1:30 p



Tuesdays with Morrie



ABC will
air the
"Tuesdays with Morrie"
story featuring
Jack Lemmon on
November 7

EQUIPMENT AVAILABLE FROM ILVA ROMANO MEMORIAL FUND

If anyone is interested in any of these devices, please fill out an application through the **Ilva Romano Foundation.**

**Respiratory Equipment:
Bi-PaP,
In-Exufflator,
Ventilator LP10**

**Walking Devices:
Adjustable cane, Folding
walkerette, Mobile sit-
down walker, Winnie
Walker, Arms rest standing
walker with wheels.**

**Transfer Aids: Lift
Chairs, Swivel seat
cushion, Multifold
ramps with Carrying
case.**

**Mobility Devices:
Guardian Transport
Wheelchair for small
frame person.**

We also have an EZ-Bathe; a vinyl tub to be used with patient in bed, comes with a hose and a wet-and-dry vacuum.



UNIVERSITY OF MIAMI
ALS RESEARCH
FOUNDATION



IMPORTANT

ILVA ROMANO MEMORIAL FUND PROGRAM

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

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

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

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

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

PATIENT SERVICE REQUEST

PATIENT

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

Home Address _____ Phone _____

City _____ State _____ Zip _____

Health Insurance _____

Responsible Family Member _____ Relationship _____

Address _____

City _____ State _____ Zip _____

Physician's Name _____ Date _____

Address _____ Phone _____

City _____ State _____ Zip _____

FINANCIAL INFORMATION

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

Other Assistance Contacted: _____

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

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

FOR OFFICE USE ONLY

Service Approved : Yes No

Total Amount: \$ _____

Authorized Signature: _____ Date _____ Phone _____

PEANUTS

BY CHARLES SCHULZ



**Don't forget to visit us on the Web
at www.miami-als.org
for more information on ALS**

IMPORTANT NUMBERS

- Kessenich Family MDA ALS Center1-800-690-ALS1
www.miami-als.org
- Muscular Dystrophy Association1-800-289-0535
www.mdaua.org
- ALS Association1-800-782-4747
www.alsa.org
- National Caregiving Fdn.1-800-930-1357
- National Family Caregivers Assn.1-800-896-3650
www.nfcacares.org
- Foundation for Hospice and 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

NOTES:

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



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

CALENDAR

SUPPORT GROUP

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

- November 20, 1999
- December 11, 1999
- January 15, 2000
- February 5, 2000

10TH INTERNATIONAL SYMPOSIUM ON ALS/MND

15-17 November, 1999
Vancouver, Canada

2ND ANNUAL EDUCATION DAY

February 5, 2000
At Student Wellness Center

University of Miami
1241 Dickinson Dr
Coral Gables
From 12:00 m. - 4:00 p.m.

GOLF TOURNAMENT

February 26, 2000
Contacts:
Tod Roy Ph: (305) 884-2352
Jose A. Perez Ph: (305) 271-9502

ALS ASSOCIATION

ALS Advocacy Day on the Hill
May 18, 2000
Arlington, Virginia.

LEADERSHIP DEVELOPMENT + ALS CLINICAL CONFERENCE

May 19-20, 2000
Arlington, Virginia

*" I am not a quitter.
I will fight until I drop.
It is just a matter of
having some faith in the
fact that as long as you
are able to draw breath
in this universe, you have
a chance*

Cicely Tyson

**HOLIDAYS CARDS
 AVAILABLE
 FOR SHIPMENT**



SEPTEMBER 15, 1999

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

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

Each packet of cards includes brief information about ALS.

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



Please Print

Ship to _____

Address _____

City _____ State _____ Zip Code _____

N° of Packages

_____ @\$17.00 per Pkg. Total\$ _____

Shp. & Hdlg. Total\$ _____

1-3 pkg. \$ 3.00

4-6 pkg. \$ 6.00

Total Amount Enclosed \$ _____