



Kessenich Family MDA ALS Center Newsletter

Volume 4, Issue 2

Summer, 2002

KESSENICH CORNER

NATIONAL ALS ADVOCACY DAY YOUR GOVERNMENT AT WORK

by Walter G. Bradley, DM, FRCP
Medical Director
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May is National ALS Awareness Month. The President of the Miami-based ALS Recovery Foundation, Kevin Packman, Esq., when an intern with Florida Senator Bob Graham, almost single handedly persuaded Congress to make this proclamation. For the last five years, the ALS community has chosen the middle Thursday in May as ALS Advocacy Day, coming in force to Washington, D.C. to lobby Congress on behalf of ALS. The ALS Association has spearheaded this process and linked it with the ALS Association Annual Leadership Development and Clinical Conference. The Muscular Dystrophy Association and the American Academy of Neurology also support many of the delegates who come to tell their Congressmen and Senators about ALS.

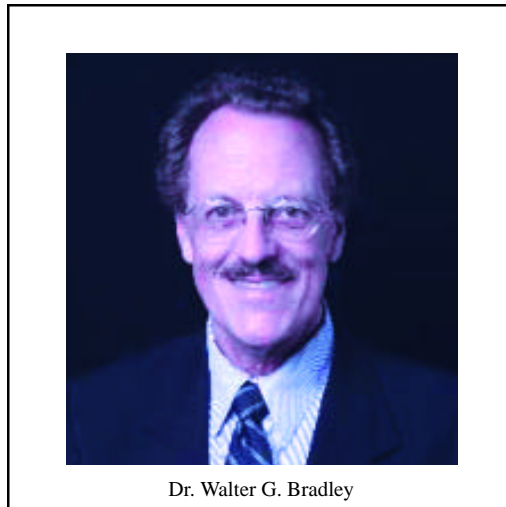
This year the South Florida Delegation and the total number of ALS advocates visiting Congress on Thursday, May 16, 2002, was the largest ever. Almost twenty patients, caregivers and professionals from South Florida joined with more than six hundred delegates from all over the United States to "invade" Congress. These lobbying efforts do pay off. Two years ago our efforts achieved the goal of persuading the Senate and the House to pass the Capp Bill that provides Medicare benefits to ALS patients one month after they receive Social Security Disability, rather than the previous situation of having to wait twenty-four months. This year the aims of the ALS community were:

1) To continue educating Congress that ALS is not a rare disease, and is responsible for one in four hundred deaths in the United States.

2) To urge Congress to increase funding for research in ALS. This includes completing the five-year program of doubling the NIH research budget, which will aid ALS research as it increases neuroscience research as a whole. This year we also included a request to pass the Department of Defense Research Budget, which will include research into the increased incidence of ALS in Gulf War Veterans and Kelly Air Force Base.

3) To advocate for a Medicare Prescription Bill to support expensive medications for ALS patients.

4) To advocate for support for families coping with ALS, including supporting S2489, the Lifespan Respite Care Act 2002 introduced by Senator Hillary Rodham Clinton [D-NY], and co-sponsored by Senator Olympia Snowe [R-ME].



Dr. Walter G. Bradley

I had the privilege of visiting with some of our own Florida Senators and Congressmen and their Staff Associates. When patients and caregivers tell their story of the devastating effects of ALS, it always gets the attention of our lawmakers. The wonderful patients and caregivers really got their message over this year. We were all impressed with the greatly increased knowledge of ALS that we have seen develop in Congress over the last three or four years. Lobbying and advocacy clearly works. The ALS community needs to get more involved, both in Washington at Advocacy Day in May 2003, and with our own Congressmen and Senators in their constituency "town hall meetings" around the state.

DOCTOR CORNER

MINOCYCLINE

By Ashok Verma, MD

A tetracycline-related antibiotic delays progression of ALS in mice.

Dr. Robert Friedlander and his group from Boston report in the May 2002 issue of the scientific journal 'Nature' that minocycline (a second generation tetracycline) delays the onset and progression of disease in the mouse model of human ALS. These genetically engineered mice harbor copies of faulty human SOD1 gene, the gene responsible for approximately 20 % of the familial ALS cases. These animal models typically develop ALS-like disease at about 90 days of their life and they die at about 130 days. Daily minocycline injections beginning very early in their life resulted in a delay of disease-onset by about 20 days and death by about 12 days. Protective effects of minocycline have previously been demonstrated in animal models of other human diseases, such as stroke, brain trauma and neurodegenerative disorders. One human clinical trial is currently in progress to investigate the effect of minocycline in Huntington's disease, a neurodegenerative disease.

How can Minocycline, a relatively common antibiotic, benefit a broad spectrum of brain diseases? It is now well known that following the very initial death

signal, the cell machinery undergoes a cascade of events during the actual process of cell death. Minocycline is speculated to inhibit one common step in the execution of this cell death program. Cyclosporin, a drug used in patients with organ transplants, is another broad inhibitor of cell's programmed death. Both these agents inhibit the release of a chemical - cytochrome c - from mitochondria (the cell's energy factory), a key step in the execution of the cell death program.

The results of the laboratory research of minocycline and ALS are encouraging for two reasons. First, it demonstrates that continued and more research efforts are needed to understand the basic cell death mechanism in order to find ways to counteract the deleterious steps in cell death process. Second, there are probably multiple potential targets that can be effectively exploited to attack the initiation, spread and progression of nerve cell death in ALS. Eventually a cocktail of different chemicals with synergistic effects at different target sites may prove to be more rewarding than just a single agent



working at one site in the cell death cascade. Currently, only one FDA-approved drug, Riluzole, is available for the treatment of ALS. Recent research indicates that this slows the progress of ALS by about 30%.

There are two currently ongoing clinical trials of minocycline to study its safety and efficacy in ALS. The results of these studies are expected later this year or early next year. Although minocycline is an FDA-approved antibiotic, ALS is not a FDA-approved indication for minocycline. Minocycline, and other tetracyclines, can produce several adverse reactions, including excessive sunburns, discoloration of teeth, headache, and bacterial and fungal overgrowth in various parts of the body. Further, long-term safety of minocycline in humans has not been established. We do not recommend that people with ALS take minocycline at this time outside of a scientific clinical trial.

PATIENT CORNER

CAN I DRIVE?

When someone has a spinal cord injury, a stroke or a disabling neuromuscular illness, one of the first questions which comes up in the rehabilitation process is, "Can I drive?" It is possible for all but the most severely disabled persons to drive safely with the advanced automobile technology available today.

ALS can affect individuals in varying ways including slurred speech, muscle weakness, poor coordination, unusual fatigue, muscle cramps, etc. Due to these symptoms, special equipment or accommodations may need to be made to aid a person in safely maintaining their mobility independence for as long as possible.

Clients with significant mobility or strength limitations can use the program's specially equipped vehicles which offer reduced-effort steering, pneumatic hand controls, touch button controls and ramp/lift systems.

A certified driver rehabilitation specialist can provide a comprehensive evaluation to determine a person's ability to drive. The assessment should include vision, visual perception, functional ability reaction time and a behind-the-wheel evaluation. Therefore, the primary goal of these services is to determine the client's capacity to operate a vehicle independently, in their environment. Further behind the wheel training is provided as needed.

WHAT PATIENTS' CONDITIONS SHOULD CUE A DOCTOR TO CONSIDER THE POSSIBILITY THAT FURTHER ASSESSMENT IS REQUIRED?

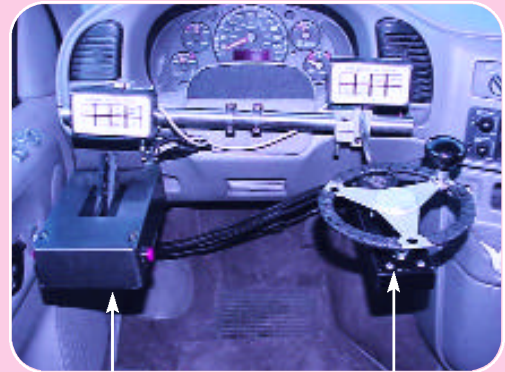
1. Has the person fallen more frequently lately: these do not have to be major falls but simply indicate that some psychomotor dexterity or balance has been lost. This can also be seen by having a person present with bruises associated with banging into objects.
2. Patients that have suffered any form of trauma, particularly to the head.
3. Patients complaining about not wanting to go out like they used to or being afraid to participate in routine daily activities that require driving.
4. Patients complaining about headaches.
5. Patients complaining that they are not sleeping well.
6. Patients that express suicidal ideas.
7. Patients that are under moderate to severe stress.
8. Patients that are using and/or abusing substances that affect driving.

ADAPTIVE DRIVING AIDS/MODIFICATIONS

With the use of appropriate adaptive aids an individual with most types of physical disability can continue to drive safely. A variety of devices are available to meet the individual driver's needs and preferences. The following is a list of the more common modifications available. They should be tried in an actual driving situation before making a final decision. (For liability issues, work with a certified adaptive driving specialist).

- Automatic transmission - replaces clutch and manual shift
- Power Steering - permits one-hand steering wheel operation
- Power Brakes - needed for hand controls and other adaptive aids
- Steering Devices - spinner knob, amputee ring, quad fork, tri pin, or custom device
- Floor Mounted Steering - floor steering wheel for foot control
- Modified Effort Steering - reduces strength needed to operate power steering or brake to accommodate low strength and/or endurance.
- Left Foot Accelerator - eliminates left leg cross-over
- Foot Pedal Extensions - raises height of brake and accelerator
- Hand Controls - control operates brake/accelerator with single lever and activates secondary controls (horn, wipers, turn signals, etc.) temporary or mounted hand controls are not recommended by Veterans Administration
- Electric Gear Selector - permits left hand operation
- Right Hand Turn Signal - permits right hand operation without cross-over
- Remote Switches - reposition or build up secondary controls (horn, wipers, turn signals, etc.) to accommodate driver's specific disability
- Seat Belts - shoulder and lap belt adjustments may be needed
- Power Seats - eases access for transferring to a regular captains seat
- Custom Seats - creates balance, positioning and stability
- Lifts and Ramps - permits access into and out of vehicle
- Wheelchair/Scooter Lifts - assists in lifting wheelchairs and scooters in and out of vehicles
- Wheelchair Carriers - permits carrying of wheelchair outside of vehicle

Sample of an actual van that contains some of our Independent Driving Systems components



Power Gas and Brake controls

Steering control



CAN I DRIVE?
 CAN I DRIVE?
 CAN I DRIVE?

PATIENT CORNER

ALS FACT SHEET

- ALS is not a rare disease.
- There are about two new ALS cases per 100,000 of the population every year. Since it is a disease that more commonly affects older people, the annual incidence is much higher in people in the later decades of life. For instance there is about one new case each year in every 5,000 people over the age of 60.
- ALS is responsible for 1 out of 400 of the deaths occurring in the United States each year.
- One in 50 families has a family member or a close friend who has suffered from ALS.
- The number of new cases of ALS each year is only slightly less than that of multiple sclerosis.

Why is ALS thought to be a rare disease while MS is considered relatively common? The reason is that patients with ALS live on the average only 3 to 5 years while patients with MS survive for an almost normal life span. There are, therefore, many more patients with MS than with ALS alive in the community.

MS and similar diseases have very big support groups and advocacy organizations raising a great deal of money to advance research into these diseases. ALS is a relatively "orphan disease", with only two organizations advancing the cause of the disease, the Muscular Dystrophy Association and the ALS Association. Though many wonderful people continue to fight to bring ALS to the forefront of the public's attention, and to raise money for the care of ALS patients and for research, there are many more people who have had loved ones die of ALS who do not continue the battle. The reason is that ALS is such a terrible and degrading disease that when the loved one has died many people want to close the door and forget about how painful the last few years were. Only if we strive to add the voices of all who have been affected by ALS to the growing chorus of protest against this disease will we raise the funds needed to find the eventual cure.

MY BOOK OF RECIPES

Nature's Best Pancakes

1/2 cup raisins
1/4 cup coconut

1/4 cup chopped almonds
1 teaspoon cinnamon

1 cup buckwheat pancake
and waffle mix

One 8-fl-oz can vanilla
liquid Ensure with Fiber

1. Heat griddle or skillet
2. In a large bowl, combine all ingredients.
3. Measure 1/4 cup mixture per package onto griddle or skillet and cook. Serve with margarine and warm syrup.
4. Pancakes can be reheated.



Basic Omelet

3 eggs
1/4 tsp. salt

1 tbsp. cold water
1 tbsp. butter or margarine

In medium bowl, beat eggs, salt and water with wire whisk or rotary beater until well mixed. (Mixture should not be too frothy.)

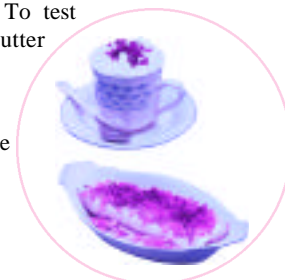
Meanwhile, slowly heat a 9-inch heavy skillet or omelet pan. To test temperature, sprinkle a small amount of cold water on skillet; water should sizzle and roll off in drops. Add butter and heat until it sizzles briskly. It should not brown.

Quickly turn egg mixture, all at once, into skillet. Cook over medium heat.

As omelet sets, run spatula around edge, to loosen. Tilt pan, to let uncooked portion run underneath. Continue loosening and tilting until omelet is almost dry on top and golden-brown underneath.

To turn out, loosen edge with spatula. Fold, in thirds, to edge of pan: tilt out onto plate.

Fill with deviled ham, liver pate, or your favorite meat blended to the proper consistency.



CAREGIVER'S CORNER

Laughter, the Best Medicine

By Dr. Victoria Bustamante
Psychologist from the Kessenich Center

Patients, doctors and health-care professionals are finding that humor and laughter may be “the best medicine”. Humor is clinically proven to be effective in combating stress, although the exact mechanism is not known. The sense of humor allows us to perceive and to appreciate the incongruities of life and provides moments of joy. These positive emotions can create neurochemical changes that will buffer the immunosuppressive effects of diseases and stress. Laughter allows us to release emotions that if we keep them inside, could be detrimental to our bodies.

Therapeutic humor is defined as the intervention that promotes health and wellness by stimulating a playful discovery, expression or appreciation of the absurdity or incongruity of life. This intervention may enhance health or be used as a complementary treatment of illness to facilitate healing or coping.

Studies have been performed to assess the effects of humor on stress. Herbert Lefcourt, from Waterloo University in Canada, reported that the ability to sense and appreciate humor could buffer the mood disturbances, which occur in response to negative life events. Dr. Derks, at the college of William and Mary in Williamsburg, has shown that there is a unique pattern of brain wave activity during the perception of humor. Humor perception involves the whole brain and serves to integrate and balance activity in both hemispheres. Dr. Lee Berk, at Loma Linda University, has performed controlled studies showing that the experience of laughter lowers blood pressure, reduces serum cortisol levels, increases the amount of activated T lymphocytes, and increases the number and activity of natural killer cells. Laughter also triggers the release of endorphins, the body natural painkillers, and produces a general sense of well being.

Humor channels “bad emotions” and helps people to feel more comfortable in tense moments. Laughter is a universal language that brings groups together and breaks down barriers. Humor is well documented to be a powerful tool in coping with life's stress, but how do you develop this skill? To increase humor in your life, look for organizations of professionals that are serious about humor. Surround yourself with funny and playful people. Everyday, search your environment for things to laugh at, observe children and animals when they are playing, watch comedy tapes, or clip cartoons that are meaningful to you.

The ability to laugh at our problems gives us a feeling of superiority and power. The interpretation of the event and not the event itself will determine if you will respond to it as threatening or challenging. Humor can foster a positive and hopeful attitude, giving us a different perspective of our problems. It can create a sense of detachment producing a sense of self-protection and control over our environment.

RESEARCH CORNER

GUAM ALS MYSTERY UNRAVELED AT LAST: FRUIT BATS TAKE THE BLAME!

By Elicia Estrella
Geneticist Kessenich Center

A disease cluster is the occurrence of a greater than expected number of cases of a particular disease within a group of people, a geographic area, or a period of time.

Clusters of various diseases have concerned scientists for centuries. One well-known, long studied disease cluster is that of ALS among the indigenous people of Guam, the Chamorros. In the 1950's it was reported that the incidence of ALS on the island of Guam was approximately one hundred times the incidence rate of the United States. It was also noted that this high incidence rate was seen specifically in the Chamorro population, but not other ethnicities/races that lived on Guam. This phenomenon is considered a disease cluster since after 1960 the incidence of ALS declined sharply.

Scientists have been intensively studying this ALS population since this cluster was first discovered. Throughout time several theories have emerged and later been rejected. Due to multiple affected people in many families, initially a genetic cause was proposed. After intensely studying these families no clear inheritance pattern could be determined. Studies of the Chamorro culture revealed the use of cycad seeds as a source of flour for cooking. The cycad seeds found on Guam are known neurotoxins. This was also known by the Chamorros who used a precise methodology of washing to detoxify the seeds during preparation of the flour.

Although this was an appealing cause for the increased incidence of

ALS among the Chamorros, scientists could never reproduce the symptoms of ALS in animals by feeding them cycads. Therefore, this theory was abandoned, as other avenues of research were more enticing.

Finally after more than fifty years of searching, scientists feel they may have an answer to the cause of this unusual disease cluster. Researchers now feel that it may indeed have been a neurotoxin that caused the extremely high rate of ALS exclusively among the Chamorros. They believe that the Chamorros may have indirectly ingested large quantities of cycad toxins through traditional ceremonial foods. The food most specifically implicated is the flying fox (*Pteropus mariannus*). The flying fox is a species of fruit eating bat that was an integral part of the Chamorro diet. This bat regularly consumed large quantities of cycad seeds, up to two to three times their body weight. When the Chamorro people then consumed the bats, they became exposed to very high levels of the neurotoxin accumulated in the bats.

Scientists believe that the high levels of neurotoxins consumed in the bats may be the causative agent in the high ALS incidence on Guam. This theory is supported by declining bat populations (to endangered levels in the 1960's) coinciding with a decrease in the incidence of ALS. This is an exciting new finding which may ultimately help elucidate

the pathophysiology of this puzzling disease.



HONORING AND REMEMBERING THOSE WHO HAVE LOST THE BATTLE WITH ALS OLITA RIVER STATE PARK



**Gone from our sight,
But never our memories
Gone from our touch,
But never our hearts**

Our first memorial service was very special, together we shared feelings and emotions. It was a meaningful memorial service for the families of ALS patients who have passed on. The words expressed by Dr. Bradley, The Reverend Gabriel Ghaanoum and Lois Murray were inspiring and encouraging to all of us. We prayed for all patients asking for strength and courage to face illness with faith and hope, as well as, the members of the health-care team that we may be filled with wisdom and courage. And especially, we prayed for those who have gone before us. The location was peaceful and beautiful



next to the water, were they had a special individual dedication. We named each individual that lost the battle with ALS, and the family members received a rose and balloon, which they released in the air, while the music was playing in the background.

Special thanks to Miami Sunset Senior High School ROTC, for the Color Guard Presentation and to our sponsors: Aventis, makers of Rilutek, Walgreen's Health Initiative, Compasionate Homecare Network, F&F Import and export and Hospice Care of South Florida.

A Gift in memory of a departed family member or friend is one of the most cherished ways to honor and remember a loved one. Many friends also make gifts to a living person in honor of who they are or for a special occasion (birthday, holiday, and anniversary). The following are unique and loving ways to remember those who have touched our lives.

I want to make a donation to support the Kessenich Family MDAALS Center

I want to make a gift of:

- \$ 1000
- \$ 500
- \$ 250
- \$ 100
- \$ 50
- Other\$_____

Your name _____ Company _____
 Address _____
 City _____ State _____ Zip _____
 E-mail _____

- Please send me information about how I can give to the Center as part of my estate.
- I/We want this donation to remain anonymous.
- Yes, my employer will match my donation.

My gift is in memory _____ honor of _____

Please notify:

Name _____
 Address _____
 City _____ State _____ Zip _____

YOUR CONTRIBUTION IS TAX DEDUCTIBLE. THANK YOU

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:

(Kessenich newsletter Volume I, Issue 1; Volume II, Issue 2; Volume III, Issue 2)

- If you live in an evacuation zone, make plans to move inland to a friend or family member's house.
- 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.
- 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

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.

- Special Needs Evacuation Centers are opened as places of safety for residents on the registry. Registrants are provided with transportation when eligible, additional medical personnel at the centers, and placement at safe facilities until the threat from the disaster is over.

Rumor Control lines (in disaster situations only):

- | | | | |
|---|----------------|--------------------------|----------------|
| -Team Metro Hotline: | (305) 375-5656 | -City of Miami | (305) 579-1800 |
| -Haitian Support: | (800) 443-2951 | -Broward County | (954) 831-4000 |
| -Florida State Emergency Information Line.. | (800) 342-3557 | -Monroe County | (800) 955-5504 |
| -TTY..... | (800) 226-4329 | -Palm Beach County | (407) 233-3500 |
| -City of North Miami Beach..... | (305) 919-0892 | | |



SALES CORNER

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Brand Name...Great Conditions.

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Contact: Call: 305-232-1480 or 305-796-7817

PATIENT TALK

ALS

America's Little Secret

by Mike Harrold

The past 2 years of my life have been an exercise of disbelief and perplexity. What I cannot believe (or at least have a hard time swallowing) is how, in the world's greatest nation, there exists a perpetual group of people with a terminal condition lacking the sufficient source of funds to find a life saving treatment? In other words, why is it socially acceptable that EVERY 12 years, we lose more people to ALS than in the Viet Nam War?

As an American, I firmly believe as a nation there is nothing we can't accomplish. Didn't we set a goal to land on the moon in the 60's? And after essentially writing a blank check to NASA, we landed and returned safely home in July of 1969. All we have to do is open the governmental checkbook and all problems can be solved.

Last year I found that the National Institutes of Health fund ALS research at about \$20 million. Compare that amount to AIDS funding which is over \$2 billion annually. (This figure is from the NIH's \$20 billion budget and doesn't include corporate research funding from pharmaceutical companies!) Having ALS is bad, but NOT allocating funds to find some life extending medication is criminal. I even searched the archives of the public budget hearings held at the NIH for the previous 3 years. The word ALS was only used 3 times, and 2 of the references were condemning the independent startup ALS foundations, such as Project ALS.

When I look over all the research programs of the NIH, there are many such as Obesity, Smoking, etc. that shouldn't even be funded by tax dollars. I can't believe and we have money to find out what happens if a person habitually eats fast food and drinks cola while smoking 2 packs of Marlboro a day. And these are not small programs. Out of the \$20 billion

annual budget, nearly half is spent on health programs that are largely self-inflicted.

After that discovery, whenever I read an explanation or definition of ALS and it states that there is "no cure", that is plain vanilla BS. All definitions should be re-stated to say that American leaders have decided not to allocate sufficient money to find a cure. It's as if someone has decided that there isn't enough money to save 5,000 people a year. And I could go along with that if it was true, but we all know it isn't. So why is it that 5,000 Americans die every year for no good reason? Any ideas?

I spend more time watching TV now than ever before. Maybe the reason is to escape from the daily burden of dealing with ALS. Ironically, instead of escaping, I find it difficult not to read inner meaning about our plight with ALS. Every time I see an underdog



in a futile situation, I can't help but think, "Heh, that is similar to an ALS patient." Or when I happen to watch a "reality show", I can't help but think "they don't have a clue as to what reality really is".

This line of thinking has even influenced my normal rational thinking with what I see on TV. Now before you think, "wow, Mike needs a different medication to pull him back into focus", hear me out. There is truly a hidden message in many of the action movies that we can learn and even apply. Let me explain.

When any of my friends ask me how I am doing, naturally I say "doing good", or "just great", when in my mind I picture Bruce Willis and Ving Rhames in the basement of Zed and Maynard's pawn shop when Bruce asks Ving,

the question "Are you OK?" If you remember the movie Pulp Fiction, Ving's response was "No man, I'm pretty %@\$ing far from OK."

What can we learn from this? If you remember the story, Ving is upset because Zed selfishly didn't serve Ving's best interest. From an ALS patient's perspective, the NIH isn't serving our best interest, either. In this analogy, we can assume Zed is the head of the NIH. How did Ving respond to Zed? Did he turn the other cheek? Oh no my friends, he was very angry.

I believe ALS patients should have the same response to the NIH for not looking out for our best interest. And until we do, not much will change. Our problem is much bigger than asking for donations in the community. As a matter of fact, my personal view is that fund raising is a massive distraction. Martin Luther King's efforts from the 60s should be our model. AIDS activism from the 80s should be another model. A coordinated effort targeting the NIH to increase funding should be our immediate priority.

Jerry Lewis addressed a congressional committee last year saying essentially that private funds "ain't gonna cut it". He said he needed help from the government to help find a cure for MD and ALS. After 50 years, Jerry had a realization. I believe Jerry needs to be there every 50 days, not every 50 years. Michael J. Foxx recently asked congress for an additional billion dollars to fund Parkinsons Research beyond the \$225 million it already gets.

It seems like Foxx is there every time you turn on the TV! We need someone like Foxx to look out for us and demand our share.

Another movie that has inspirational overtones and hidden messages is Gladiator. Early in this movie, the main character Maximus, played by Russel Crowe, is lauded for being a heroic general in the Roman army. Soon, he is dealt a situation outside his control and his life is threatened by the same group that had praised him minutes before. Later, Maximus' family is wiped out and his home destroyed. Maximus becomes a slave gladiator serving Proximo. Proximo tells Maximus "win the crowd and you'll win your freedom". That message for ALS gladiators is if we can win over the American public or elected officials, then we can gain the funding to find a cure.

ALS America's Little Secret

So how do we win the crowd? Let me ask a different question. What is the difference between 3,000 people dying in the World Trade Center tragedy and 5,000 people dying from ALS every year? How is it that over a billion dollars were donated in a few short months to the victims of 9-11-01 from the American public? What is the difference and what are we missing?

As bad as the WTC disaster was, it helped me classify our own disaster. Until then, I tried to swallow the simplistic concept that it was OK for 5,000 people to die every year for no good

reason; that it was OK for 25,000 families to slowly disintegrate every year. The numbers are eerily similar. Each tower could hold 25,000 people – the same number of ALS patients. And the final death toll was 3,047 almost half of what we lose every year.

The response to terror by the nation was to throw billions of dollars at the problem—almost over night! America said “NO to terrorism”. I am asking how do we get America to say NO to ALS? What are we lacking? How do we get the message across? I don't have any answers today, but some areas to think about are the differences in the tragedies, namely: 1) speed or rate of incident, 2) geographic density of concentration of

victims, 3) time duration of death toll, 4) dramatic effect of devastation (what I call the inaccurate assumption of ‘no flame - no pain’).

In conclusion, I believe we need an immediate and concentrated effort to increase funding at the NIH for ALS. Additionally, increase the effort to “win the crowd”. We desperately need more drama. A crude example is for every new diagnosis of ALS, make it mandatory that the patient drive home distraught and crash into the garage with foot firmly pressed on the gas pedal. Of course, don't drive into your driveway, but rather an unfriendly neighbor. Fifteen incidents a day should build media attention after a few weeks! Remember, think Win-Win-Win the Crowd-Crowd-Crowd!

GLOSSARY OF ALS TERMS (Part II)

Home Health Care

Health Professional giving services at home (PT, OT, nursing).

Home Mechanical Ventilation

Use of mechanical ventilator at home for respiratory support.

Hoyer Lift

A mechanical device used to transfer non-ambulatory patients when he/she becomes too difficult to move by other means.

Hospice

An institution that provides a centralized program of palliative and supportive services to dying persons and their families, in the form of physical, psychological, social, and spiritual care.

Hyperreflexia

Exaggerated reflexes. In hyperreflexia, only a slight stimulus is needed to initiate a reflex response.

Life Support

Point at which a patient suffers respiratory failure and needs full-time respiratory support, i.e. Mechanical Ventilator.

Medicare

National Federally funded health insurance Program for the elderly and, since 1973, the disable.

Muscle Atrophy

Wasting of muscle mass.

Muscle Cramps

Painful shortening of muscle or palpable knotting of the muscle.

Muscle Weakness

Loss of strength or variation in strength, fatigability.

Physical Therapy

Treatment given at regular intervals with the purpose of maintaining muscle strength and range of motion to avoid contractures and frozen joints.

Pulmonary Function Test

Also known as PFTs, is used to evaluate the nature and extent of pulmonary disease and to identify the underlying ventilatory impairment as obstructive and/or restrictive.

Range of Motion

(ROM) Passive movements done to joints with the purpose to maintain flexibility and to avoid contractures. These exercises can be done by self or by caregivers.

Sialorrhea

(Drooling) Excessive pooling of saliva in the mouth due to lack of spontaneous automatic swallowing.

Spasticity

Sustained increases in tension of a muscle when lengthened.

Support Groups

Support groups are of great help for patients and for those involved in the care. These types of groups as well as spiritual and emotional support many times also provide educational presentations.

Swallowing

The swallowing track extends from the mouth to the stomach. The normal swallowing consists of four stages: The oral preparation stage: biting and chewing. The oral stage: tongue propulsion, to move food from the front to the back of the mouth. The pharyngeal stage: the airway closes to prevent aspiration. The esophageal stage: involves muscle contraction that propels the bolus through the lower esophageal sphincter and into the stomach.

TDD

(Telecommunication device for the deaf) assisted service through the phone company, can also be a good device for those with speech impairment.

Tracheostomy

Opening into the trachea through the neck. Tracheostomy is the most common method for administering long-term mechanical ventilation to ALS patients.

Wheelchair

Equipment used to ambulate when unable to walk. Especial assessment is required for every individual's specific functional needs.



IMPORTANT NUMBERS

| | |
|--|---------------------------------------|
| Kessenich Family MDA ALS Center | 305-243-7400 |
| | 1-800-690-ALS1 |
| | www.miami-als.org |
| Muscular Dystrophy Association (National Patient Information) | 1-800-572-1717 |
| | www.mdausa.org |
| • St. Petersburg | 717-576-5202 or 1-800-393-8552 |
| • Palm Beach Gardens | 561-242-5084 or 1-800-289-0535 |
| • Miami | 305-717-9937 or 1-800-572-0085 |
| • Broward | (954) 757-4357 or 877-970-9696 |
| • ALS Association in Florida | 1-888-257-1717 |
| ALS Association | 1-800-782-4747 |
| | www.alsa.org |
| National Caregiving Fdn | 1-800-930-1357 |
| National Family Caregivers Assn | 1-800-896-3650 |
| | www.nfcacares.org |
| Foundation for Hospice and Homecare | 202-547-6586 |
| National Hospice Org. | 1-800-658-8898 |
| A.D.E.L.A. Asociación Española de Esclerosis Lateral Amiotrófica | www.advernet.es/adela/index.htm |
| Social Security Online | 1-800-772-1213 |
| | www.ssa.gov |
| The Feeding Gastrostomy Information: | www.iinet.net.au/~scarffam/gtube.html |
| ALS Digest (Bob Broedel): To subscribe, please e-mail to | bro@huey.met.fsu.edu |

If you need a referral to see one of our satellite centers, please call at 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 have had experience with ALS patients and now have time to volunteer.**



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MDA ALS Center
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Miami, FL 33136

*A happy person
is not a person in
a certain set of
circumstances,
but rather a
person with a
certain set
of attitudes.*

Hugh Downs

CALENDAR

- **Support Group Dates**
Saturday, August 17, 2002
“ September 14, 2002
“ November 9, 2002
“ December 14, 2002
- Location: University of Miami
Hospitals & Clinics
1475 NW 12th Avenue
Room 1301
12:00 - 1:30 pm

- **Support Group for Caregivers only**

- Saturday, July 13, 2002
“ October 12, 2002

- **Annual ALS Symposium at
The University of Miami**

Saturday, November 9, 2002

Place to be announce