

Finding a Silver Lining...

The following message demonstrates the heart and passion that Kurt Goeser has found within his journey living with ALS. Kurt shared this recently in an address to the congregation of the First Presbyterian Church of Austin at what he called his 'coming out'.

Who am I? My name is Kurt Goeser, I am 42 years old, a husband to my beautiful wife Brenda, and father to two amazing kids, my son Daniel (6) and my daughter Tessa (4). Like my mother in Wisconsin, I am the youngest of 5 children, the middle-class product of a Midwestern farm town. I graduated from the US Naval Academy, served my country with pride, earned a graduate degree, and embarked on a business career with some success. I have led an amazingly lucky, exciting, and full life. I've traveled a good part of both hemispheres, crossed 3 of 4 oceans and have all kinds of friends of just about every color and creed. I am a do-it-yourselfer, an outdoorsman, foody and fisherman, but these days, mostly a father. By *any* measure, I am a lucky man. Unfortunately I have some sad news to share.

My disease? A few weeks ago I was diagnosed with a terrible motor neuron disease called Amyotrophic Lateral Sclerosis (ALS), also known here as Lou Gehrig's Disease. ALS is a degenerative condition which affects our voluntary muscles. Essentially, the electrical connection from the brain, thru the spinal cord and motor neurons stops working, one muscle fiber at a time. Without the neural impulse, eventually the muscles of the body die. While every individual's progression is different, as the disease advances, ALS patients eventually become quadriplegic, and require respiratory and nutrition support, in other words...**Special handling**.

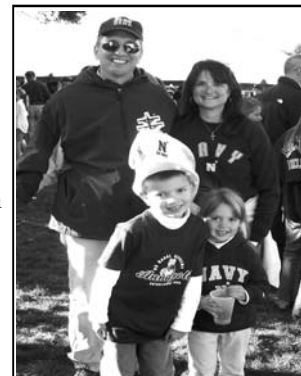
With rare exceptions, ALS does not affect cognition significantly. Also, the heart, and usually the muscles of the eyes are unaffected. A person with ALS retains all of his/her senses, and mental capabilities, just doesn't have the body to

go with them.

Advances in technology allow people with ALS to communicate throughout the progression of the disease. Classified as an 'orphan disease', ALS strikes an estimated 5,000 Americans every year. There is no known cause, limited treatment, and no cure, yet. ALS strikes all kinds of people everywhere and veterans are twice as likely to contract the disease.

Where are we now? Obviously, Brenda and I, our family and friends, have been devastated by this news. I think we are over the initial shock and trauma of the diagnosis, and are well into coping. Brenda has been incredibly strong throughout this process; she has kept my head up, and kept us moving forward. I am lucky to have a good job with a great company that I think will continue to be very supportive and I plan to continue working for as long as I can.

We have an incredible support network, including some of the best neurology and ALS specialists in the world working with me in Houston. Our primary concern is naturally for our children, now and in the future. Brenda and I consulted a friend and prominent child psychiatrist after I was diagnosed to get some council on how best to handle it with Daniel and Tessa. Curiously, he spent most of the time examining my head. His advice regarding the children was to give them enough information to explain honestly what was going on, but not so much that they get scared about things that haven't happened yet, or think they are somehow a part of a "disease". 'Let them continue to be kids, don't make them caregivers, but let them help'.



Kurt Goeser with his wife Brenda and children Daniel and Tessa at a Navy game.

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A Simple Gesture

Everybody can be great....because anybody can serve. You don't have to have a college degree to serve. You don't have to make your subject and verb agree to serve. You only need a heart full of grace. A soul generated by love.

Martin Luther King, Jr.
(From Chicken Soup for the Soul, Volume 1)

Care for the Caregiver. *In honor of all caregivers we offer the following article written by Alison Teichgraber. This is the second part of her article titled 'An ALS Caregivers Perspective' and was written in memory of Patrick Teichgraber 1964-2004..*

Stay ahead of ALS

ALS is a relentless foe. By staying ahead of ALS, you have more chances to be prepared for the unexpected twists and turns the disease can make.

Have PALS use a walker before one is needed. There is nothing worse than falling and getting stuck. My husband was once stuck on the floor for 30 minutes before I came home from work. My kids found him on the floor and they all had a good (albeit embarrassing) laugh.

Order the wheelchair before your PALS needs it. It can take months (with a capital S) to receive the chair and only one fall or the flu to suddenly need one.

Allow time for your PALS to adjust to the bi-pap. My husband HATED it. By “practicing,” he slowly got used to his “space mask.”

ALS is part of your life NOT your whole life

An ALS caregiver experiences the same challenges as the ALS patient. Each step along the ALS path can be debilitating, exhausting, and overwhelming. But, it is only part of the picture. There is much more to life than ALS. It is important to pay attention to the other aspects of your life such as your children, education, and friends.

We all know life doesn't always give us roses; it sometimes gives us lemons. By enlisting friends and family, you can help yourself and your PALS make lemonade. One of the most challenging tasks of a caregiver is making life feel as “normal” as possible. People who are not used to the changes ALS may cause feel uncomfortable and it is up to the caregiver to help ease this discomfort.

I suggest keeping a “chat list” list like this one available for visitors who feel squirmy.

Simple Ways to Feel LESS Uncomfortable Visiting PALS

Talk about the weather

Talk about your kids

Talk about SPORTS!

Talk about your work

Talk about the PALS

Don't talk, just enjoy the game/movie/etc.

Bring a friend/spouse/child

And, sometimes, a visit with few words spoken is the best visit of all.

ALS can be isolating. It is up to you to reach out to others for not only your PALS but also for yourself. Although spending 1/3 of your time on yourself, 1/3 of your time on your family, and 1/3 of your time on your career is probably impossible, it should be a goal to strive for. Balance in life is optimal. By taking care of yourself, educating yourself, asking for help, staying ahead of ALS and not allowing ALS to be your whole life, you can be the best caretaker possible.



Mission Statement *The ALS Association, Greater Houston Chapter is dedicated to patients, families, and friends of those affected by Amyotrophic Lateral Sclerosis (ALS, also known as Lou Gehrig's disease). Through patient services and support, advocacy efforts, public awareness and education, as well as enabling research for a cure, we thrive to improve the quality of life for all PALS.*

Show Your Colors by wearing Red



'Strike Out ALS' Wrist Band

Wrist Bands are \$1.00 each.

Order them for family, friends, coworkers, and Walk to d'Feet team members.

Minimum order is 10 wristbands. There are #50 wristbands per bag for those wishing larger quantities. Order by phone, fax, e-mail, or mail.

Mail Order and Payment to:

ALS Association
Greater Houston Chapter
PO Box 271561
Houston, TX 77277-1561

Add \$3.50 per #50 for shipping.

A Special 'Thank You' to the following companies for providing lunch for ALS Clinic days:

**Adorno-Rogers Mobility
Hill-Rom
Honeybaked Ham
Memorial Hermann Home
Health Care
Sanofi-Aventis**

Form a Fundraiser

Forming a fundraiser is another great way to bring awareness to ALS and support your local chapter. We'll help make your event a success for you and for ALSA-Greater Houston Chapter 713-942-2572.

THE ALS ASSOCIATION DONOR PRIVACY AND CONFIDENTIALITY POLICY

The ALS Association, Greater Houston Chapter honors the rights and privacy of our donors. We do not sell, trade, or share our address lists or mailing lists

Silver Lining continued from page 1

So for right now, Dad's legs aren't working so great, he needs a cane and foot-brace to walk, and a little extra time to do just about everything. This week when I told our son Daniel that I was going to the doctor, he asked "Dad, what if your leg doesn't get better?" When I replied "Well, I'll still be your dad, won't I?" he thought that was just hilarious.

This disease is different for everyone, but I feel ALS has come up on me fast. Four months ago I was riding my bike 10 miles in the hills around my neighborhood. Today I struggle to walk up a ramp against a stiff breeze. But I am working hard against the onset of the disease, mainly thru nutrition and fitness. The doctors I trust and respect the most, who are incredibly committed, even obsessed with finding a cure for this disease, tell me that the conventional wisdom about the survival of ALS patients can no longer be accepted, that *patients are living longer, better lives*.

So now most mornings you can find me swimming slow laps in the pool, and I start and finish the day with an awful potion of vitamins and assorted foul tasting powders. I also start and end every day with a simple prayer, which occurred to me the first day I was diagnosed: "Father, thank you for another day with ALS".

What next? In a nutshell, my plan is to continue being me, adapting to my condition, and living each day as an event. Brenda and I are committed to making a memory for our family every day, and I don't think we have ever been more in love. If you can, I highly recommend living a few days like you have ALS. You will be amazed at how you appreciate the simple *beauty* of life, how little you worry about *unimportant* things, and *make* time for important things, such as, how much and how well you talk to your friends.

I also plan on following thru on a commitment I made to God. I have led an incredibly blessed life, and have a profound desire to give something back to the world. While not the opportunity I was *anticipating*, I now have an *amazing* one to pursue. Despite my limited, but growing, experience and knowledge of how people deal with this disease, I think there is a lot of room for improvement. Some friends and I plan to raise money and awareness to help less fortunate ALS patients and fund much needed basic research.

What do I need? *Time*, but time flies. I need a *miracle*, but I believe I have *already* been blessed with a couple. I believe that God grants us miracles all the time and that they often go unnoticed, until they are revealed by unforeseen circumstances.

I ask a couple of things of my friends regarding my condition. First, if you can think of it, please don't say to me "I'm so sorry for you", only because I am trying very hard *not* to feel sorry for myself. I have a lot to be thankful for. No offense intended, but the *doctors* don't know how much time I have left, *I* don't know how much time I have left, and frankly *neither do you*. I prefer that you greet me with a "Good to see you", or a "Hang in there", or my favorite "May Peace be with you". Offering your thoughts and prayers for our family is greatly appreciated and I figure the more people that put in a good word for us with God the better.

I also request that you say a prayer for yourself. Say a prayer now, for what you hold *dearest*, for what you take *most* for granted in your life. Pray for your Faith, that it will sustain you when you need it most, Pray for your Hope, which you have for your future, and Pray for the Love, which surrounds you every day, and is hidden deep in your heart.

The following events helped make 2006 the best year ever for ALSA Houston.

• 1st Annual Chad Hedrick 'Go for the Gold' Golf Tournament

Chad Hedrick showed his stuff at the 2006 Winter Olympics in Torino, Italy and did it again with a great golf tournament which raised funds for The Special Olympics and for ALSA Houston. Thanks Chad, you're the best.

• 2nd Annual Ferguson Elementary School "D'Feet ALS"

Students from ages 5 to 11 sold feet they then decorated and displayed around their school. They again raised money and awareness for ALS. Goes to show you that you are never too young to help other. Thanks kids, great job!

KEEP ACTIVE, INDEPENDENT, SAFE, AND COMFORTABLE

Claire Sweatt MacAdam, PT, NCS
Baylor College of Medicine
ALS Clinic Coordinator

*You may have some questions.....*What can I do for myself? How much should I exercise? How active should I be?

These are questions often posed by individuals with ALS. Gratefully we have some suggestions and guidelines to offer learned from years of working with ALS patients and their families.

So settle back, relax, and let me share...

It's good for the body, mind and soul to be active, independent, safe and comfortable. Here are some ideas to help you achieve these goals:

Exercise is good. It keeps the body as healthy and fit as possible. Exercise keeps your heart strong, encourages deep breathing, keeps circulation flowing, helps the digestive system, promotes joint flexibility, and provides an overall sense of relaxation.

Your exercise program should include:

- **Stretching** – daily stretching keeps joints limber and flexible. Shoulders, hips and ankles can tend to tighten if not moved frequently. Try to gently stretch each day. Stretching should be done slowly and easily. Never force, jerk, or bounce. A Physical Therapist and Occupational Therapist can help set up a stretching program uniquely designed for you.
- **Aerobic activities** – these are the types of exercises that give your whole body a workout, exercising your heart, lungs, and muscles. Think about a walking program, a stationary bike, or a pool therapy program. Remember, it doesn't have to be rigorous or fatiguing . . . even just a short walk or a few minutes on a bike can be helpful.
- **Avoid excessive fatigue or exertion** – exercise is great but listen to your body and decide what you are comfortable doing. It's best to avoid pushing yourself too hard. On good days, have fun with exercise and on not-so-good days, rest and just try some simple stretching.

Consider using assistive devices. They provide help and allow you to continue to be active, independent, safe, and comfortable. Adding assistive devices can seem overwhelming and frustrating at times but the important questions to answer are:

- Will this allow me to still do my daily activities **independently**?
Example: Using a device called a buttonhook lets you hook your own buttons instead of having someone help you button your shirt
- Will this allow me to still do my daily activities **safely**?
Example: Using a rolling walker and simple ankle brace can allow an individual to walk safely and avoid falls
- Will this help me be more **comfortable**?
Example: Adding a wedge to your bed that props you up when sleeping can help you feel more comfortable and relaxed when sleeping

There are assistive devices for every possible need and finding the items that are just right for you can take some searching. Consulting with a Physical Therapist and Occupational Therapist can help you navigate through all of the choices. The primary goal of your health care team should be to do everything possible so that you remain safe, active, independent and comfortable.

The ALSA Capitol Report

ALS Registry Act:

This year we generated tremendous support for the ALS Registry Act (HR 4033 / S 1353). We began the year with 68 cosponsors in the House and ended with 215. In the Senate we added 33 cosponsors this year for a total of 50 Senate cosponsors. We kept our advocacy efforts up until the end of the legislative session and gained two new cosponsors in the House on the final day.

- When the 110th Congress is seated the ALS Registry Act will have to be reintroduced and we will be reaching out to you again to request that you contact your Members to sign on. The
- A final list of cosponsors is available on the Advocacy Action Center of our website.



ALSA Houston had five constituents who attended 'Advocacy Day 2006'. Meeting with local congressional representatives and their staff was a highlight for all. Thanks go to Alison Teichgraber, Chris and Reda Rice,

House and Senate Pass the Lifespan Respite Act

Prior to adjourning for the year the House and Senate **passed the Lifespan Respite Care Act (HR 3248)**. This is a tremendous victory for people with ALS and their families. The bill authorizes \$289 million over five years for respite care programs across the country and will help people with ALS and their families access much needed respite services. Importantly, because the funding is provided to the states, ALSA Chapters may be eligible for state respite care grants that become available as a result of the increased funding. President Bush signed the bill on December 21, 2006. Now the Department of Health and Human Services (HHS) must determine a process for distributing grants to states, and states must also determine how they are going to use the grants.

Thank you to everyone for their hard work in support of the Lifespan Respite Care Act over the past several years. As many of you know, this legislation was a priority at our 2005 Advocacy Day as well as for the I Took the Extra Step Campaign. This is another victory for people with ALS and their families. There is more work to be done to establish criteria on the state level. Again, your support is requested.

Andrew Von Eschenbach Confirmed as FDA Commissioner

On Thursday, December 7, 2006, Dr. Andrew Von Eschenbach was confirmed as the new Commissioner of the Food and Drug Administration (FDA) by a vote of 80-11 in the Senate. The FDA is the federal agency that approves the sale and manufacturing of drugs, medical devices and biologics. Dr. Von Eschenbach, a urologist and former Director of the National Cancer Institute, had been Acting Commissioner since September 2005. Dr. Von Eschenbach has experience with patient advocacy organizations and is a cancer survivor, so he knows the importance of finding a treatment and cure for disease.

FDA issues are expected to be on the agenda of the 110th Congress. Congress is set to reauthorize the Prescription Drug User Fee Act (PDUFA), which allows the FDA to collect fees from drug companies to speed the new drug-approval process, a priority for The ALS Association.

2007 National Advocacy Day

2007 National Advocacy Day and Public Policy Conference will take place from **May 14-16, 2007** in Washington DC. If you are interested in attending, you may register online at www.alsa.org/policy/alsday.cfm. Be part of the ALSA Greater Houston Chapter group and share a memorable time of learning not only more about Advocacy, Research, and ALSA but about the working of our legislative system. Please let the chapter know that you will be attending by contacting us at 713-942-2572. We welcome you to share this motivational and educational experience with our staff, volunteer, patient, family, caregiver, and healthcare contingent.



Get out your Walking Shoes and Walk to d'Feet ALS®

**BE A PART OF THE LARGEST NATIONAL
ALS EVENT THIS YEAR!**

Thousands of ALS patients would give anything to walk.
Many can't. *Will you walk for them?*

4th Annual Sugar Land Area Walk

Sunday, March 4 · 8 am Registration · 9 am Start

1st Colony Mall, 16535 Southwest Freeway, Sugar Land, TX (Corner of Hwy 59 South and Hwy. 6)

Start Today....Create a Walk Team and ask anyone and everyone you know to join the effort to raise money for ALS. Family members, friends, neighbors, co-workers, children, adults. ***Walk Teams And Walkers come in all shapes and sizes.***

Simply name your team, register on-line, create your Team Page, and get going. Let's make this our most successful walk ever. Our goal is to raise \$50,000 from this walk. Get on board and help make our wish a reality.

To Register or Donate NOW!

www.alsa-houston.org

or contact us at 713-942-2572

Fall Walks:

3rd Annual College Station Area Walk

Saturday, October 20, 2007 · 9 am Registration · 10 am Start
Central Park, Krenek Tap Road, College Station, TX

4th Annual The Woodlands Area Walk

Saturday, November 10 · 9 am Registration · 10 am Start
Montgomery College, Hwy. 242 at I-45 North
The Woodlands, TX 77381

NEW WALK....We are planning to add ***The Bay Area Walk in the fall of 2007.*** Interested???
Contact us at 713-942-2572. Date and location to be announced.

WANTED....All Pictures

Please send us a picture of a loved one who has ALS or who has lost their life to Lou Gehrig's Disease.

We are creating an ***ALS March of Faces*** banner which will be displayed at upcoming events. Provide a picture (we are unable to return pictures, so make a copy), full name of the person, their date of birth, date of diagnosis, and date of passing, if in memorium.

Help us educate the world about ALS and those whose life it affects and whose life it takes.



The ALS Association Launches TREAT ALS to Accelerate Drug Discovery for Lou Gehrig's Disease

Roberta Friedman, Ph.D.
ALSA Research Department Information Coordinator

The ALS Association's new initiative **TREAT ALS** [Translational Research Advancing Therapy for **ALS**] combines efficient new drug discovery with priorities set for existing drug candidates, to accelerate clinical testing of compounds with promise for the disease.



"Now tangible progress will be turned towards patients to produce treatment success," according to Lucie Bruijn, Ph.D., ALSA's science director and vice president. "Translational research and clinical trials will find the drugs which will prevent, halt, or significantly slow down disease progression."

"Our ultimate goal is to capitalize on scientific and technological progress to accelerate drug discovery and realize effective new therapy," said Dr. Bruijn. "We understand far more about the biological basis of the disease and this knowledge has enabled design of laboratory models of ALS that have yielded innovative ideas and novel treatment strategies."

Already partnering with many organizations around the world including The National Institutes of Health (NIH), the largest single investor in research globally, ALSA brings together an expert team of scientific and business advisors to steer this initiative. "As part of this initiative we will support the development of novel compounds for large scale, U.S. Food and Drug Administration approved clinical trials and engage in small pilot trials of existing FDA-approved drugs," said Bruijn.

Noted biologist Tom Maniatis, Ph.D., Thomas H. Lee Professor of Molecular and Cellular Biology of Harvard University, is head of the ALSA-initiated program and has played a leading role in shaping this new focus. "As we continue to aggressively push forward on ALS research it is important to maintain our focus on the discovery and development of new ALS drugs," Maniatis said. "TREAT ALS is an exciting initiative that will translate advances in research in academia and industry into drug development and clinical trials. I look forward to working with an outstanding group of scientists and neurologists on the TREAT ALS steering committee to intensify the search for an ALS cure."

ALSA's new initiative aims to move good ideas from the research arena more rapidly into the clinic for clinic trials and then patient treatment. This initiative does not currently provide new therapies and is designed as a research initiative, not a short term treatment initiative. To learn more about what's new in research visit <http://www.alsa.org/research>

In Memoriam

Martha Alexander	Terry Paul Matthews
Paul Barrett	Melbourne McDonald
Russell Butard	Edwin Miller
Ted Capps	Kathy Parker
Kaye Hodges Close	Mary Pieniazek
Maggie Farlow	Glen Ryan
Monte Frierson	James Stallings
William 'Clinton' Holleman	Cassandra Steedley Delia Sumrow
Edward Horan	Dorothy VanNordstrand
Sammy Jones	Rene Wallace
Elizabeth Kerr	Delson Young
Jimmy Don Lowry	David Zion

We extend our sympathy and support to family and friends of those we've lost. If we have neglected to include the name of a loved one, please accept our apologies and contact our office 713-942-2572.

INTRODUCING: FRIENDS OF ALS

Be partnered with someone who is or has experienced ALS in their lives and have a friend to share and visit with by phone on a regular basis.

- **Volunteer 'Friends of ALS'** are people who want to offer support and a helpful ear.
- **Patient/Family 'Friends of ALS'** need that ear and welcome an occasional gentle contact.

Call our office to register for this great program, 713-942-2572.

ALS CONNECTION...Monthly group meetings

North Area: 2nd Tuesday, 6:30 pm, Spring Woods United Methodist Church, 1711 FM 1960 West, Houston, TX 77090, business office entrance.

Central Area: 3rd Sunday, 2 pm, The Hampton at Tanglewood, 505 Bering Drive, Houston, TX 77057, 3rd Floor Living Area.

Meetings are FREE and open to all who are or have experienced ALS in their lives.



The ALS Association
 Greater Houston Chapter
 PO Box 271561
 Houston, TX 77277-1561

There are Many Ways to Help!

WORKPLACE GIVING... *Community Health Charities of Texas (CHC) allows you to designate where you want your healthcare contributions to go. To have your donations directed to ALSA, Greater Houston Chapter, use the following codes on the CHC of Texas pledge form.*

- **Community Health Charities of Texas (CHC) #1302**
- **State Employee Charitable Campaign (SECC)# 050001**
- **National Combined Federal Campaign (CFC) # 0501**
- **City of Houston (CMC) # 5603**

To set-up a CHC of Texas workplace giving option, contact 713-828-2853 or 888-839-4325.

UNITED WAY must write in: **ALS Association, Greater Houston Chapter, PO Box 271561, Houston, TX 77277-1561**

Thank you for continued support of The ALS Association through Community Health Charities and the United Way.



- Link your **Randalls Remarkable Card** to our account **#11123** (at courtesy booth).
- Call 713-942-2572 to request a **Kroger Share Card** and it will be mailed.

Randalls and Kroger donate a percentage of your total purchases to ALSA Greater Houston Chapter, so be sure to use your card when you shop.

VOLUNTEER TODAY... We depend on volunteers to support programs and fund raising activities. You are the driving force behind our efforts. To help, please contact us at 713/942-2572, 1-866/778-ALSA, www.alsa-houston.org

DONATE ITEMS FOR OFFICE: We need it all and your help is greatly appreciated. From desks and chairs, to computers, copier, printers, filing cabinets, coffee maker, cups, couch, tables, bookshelves.....you name it. If an office uses it we need it. Let us know how you can help and we'll arrange pick-up. Thanks!

EQUIPMENT LOAN PROGRAMS: Have equipment you are no longer using? Your donation to our loan program will help other ALS patients, 713-942-2572.

ALS Association, Greater Houston Chapter meets the Charity Standards set by the Better Business Bureau of Metropolitan Houston.