



The Amyotrophic Lateral Sclerosis Association
 Greater Los Angeles Chapter
 P.O. Box 565
 Agoura Hills, California 91376-0565

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Volume 1, 2003

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Our Mission:
 It is the mission of the Greater Los Angeles Chapter of The ALS Association to provide meaningful assistance for persons with ALS, their families, caregivers and health professionals in the Greater Los Angeles area.

UPCOMING EVENTS

- 5/1/03
Advocacy Day, Capitol Hills, Washington D.C.
- 5/2-3/03
ALSA National Leadership Conference, Washington D.C.
- 5/17/03
"Ask the Experts, Fearless Living with ALS - II"
 Invitations to be mailed during the first week of April!
- 6/19/03
Lou Gehrig's 100th Birthday!
 Look for more information on upcoming events in the mail!
- 7/21/03
Authentic Swing Charity Golf Tournament, North Ranch Country Club, 9:00 a.m.
- 10/4/03
"Walk to D'Feet ALS Charity Walk," Reed Park, Santa Monica. Preparations are beginning now to make this year's walk better than ever!

SAVE THE DATE!



UPCOMING EVENTS

- May 1, 2003**
Advocacy Day, Capitol Hills, Washington D.C.
- May 2-3, 2003**
ALSA National Leadership Conference, Washington D.C.
- May 17, 2003**
"Ask the Experts, Fearless Living with ALS - II" Invitations to be mailed during the first week of April!
- June 19, 2003**
Lou Gehrig's 100th Birthday! Look for more information on upcoming events in the mail!
- July 21, 2003**
Authentic Swing Charity Golf Tournament, North Ranch Country Club, 9:00 a.m.

October 4, 2003
"Walk to D'Feet ALS Charity Walk," Reed Park, Santa Monica. Preparations are beginning now to make this year's walk better than ever!

If you would like to host a fundraising event, please contact the Director of Special Events, Giovanna D'Angelo at the chapter office.

(818) 865-8067 • www.alsala.org • events@alsala.org

GOLF TOURNAMENT SCHEDULED FOR JULY 21 AT NORTH RANCH

The ALS Association, Greater Los Angeles Chapter will be hosting the 3rd Annual "Authentic Swing" Golf Tournament on Monday, July 21, 2003 at North Ranch Country Club in Westlake Village. The event will feature an 18-hole scramble format tournament, putting contest, silent auction, live auction, and dinner reception. Registration is limited, so please contact the office immediately to register for this enjoyable and beneficial fundraising event. Sponsorship packages are being distributed now for this event. If you are interested in becoming a major sponsor for this event or would like to donate a silent or live auction item, please contact Giovanna D'Angelo at the chapter office. For more information or to register, please call (818) 865-8067 or visit the web site at www.alsala.org. **Save the Date!**

CHARITY SOCCER MATCH TO BENEFIT THE ALS ASSOCIATION

An exhibition mens' soccer game featuring Cal State-Bakersfield and UCLA will help to raise funds for The ALS Association of Greater Los Angeles Area Chapter. The game will take place under the lights on April 11, 2003 at 7:00 p.m. at the soccer field on the Cal State - Bakersfield campus. Tickets are \$12 for adults and \$6 for children and seniors. A portion of the proceeds will benefit The ALS Association, Greater Los Angeles Chapter. For more information, please contact the office at (818) 865-8067 or via the web site at www.alsala.org.

MESSENGER

THE ALS ASSOCIATION, GREATER LOS ANGELES CHAPTER SERVING LOS ANGELES COUNTY • SAN BERNARDINO COUNTY • VENTURA COUNTY

BARBARA PHILLIPS NAMED "NATIONAL POINT OF LIGHT" AWARD WINNER!



Barb Phillips (second from left), was the recipient of the December 12, 2002 "National Point of Light Award for Volunteer Service." Barb is pictured here with PALS Hosea Fortuné, CART volunteers, and friends.

The Points of Light Foundation, founded in 1990 by former President George Bush, is a national organization that promotes and celebrates volunteerism. Each weekday, there is one Daily Point of Light Award given, acknowledging an individual or group's extraordinary contribution to their community. On December 12, 2002, our own Greater Los Angeles Chapter volunteer, Barb Phillips from Rancho Los Amigos National Rehabilitation Center, won this prestigious national award for her work with the Simple Wishes program!

Simple Wishes began as an idea Barb had after spending several months with her father, Pete Weintraub, while he battled ALS back home in New York. During that time she often found herself frustrated at not being able to demonstrate her love for him in old, familiar ways. Pete no longer could eat the delicious chocolate chip cookies Barb used to bake, or had any use for one more brightly colored Hawaiian shirt. On the recommendation of a friend, Barb asked her dad, of all the things in the world, what would be a task that she complete for him. His answer was so simple. All he really wanted was for the family home to be made ready for the upcoming winter. Barb and her brother, Steve, started immediately. Working side by side they covered the screens with sheets of plastic, fixed a leaky faucet and stocked up on paper products. After the jobs were completed, there was a sense of peace that filled the home.

In August of 2000, Barb shared her experience and idea with Molly Rockey, Director of Volunteer Services for the Greater Los Angeles Chapter. Together they brainstormed on how to create a program that could provide the completion of meaningful tasks for PALS by volunteers- and Simple Wishes was born. To date there have been 39 Wishes completed. Volunteers from Rancho Los Amigos have trimmed rose bushes, written love letters, compiled scrapbooks, organized family recipes and sorted through and rearranged old 45's for a jukebox. They have helped write a letter to the FAA, complete a book of poetry, sat and watched a Laker game, facilitated trips for families and cooked a special meal from a favorite recipe. Because Barb was willing to give her idea wings and worked tirelessly to organize dozens of volunteers, the Greater Los Angeles Chapter nominated her for the National Points of Light Award. This award honors the memory of Pete Weintraub, inspires staff and volunteers to continue their work with the ALS community, and celebrates the power of even the simplest "wish".

NEWS!
 Visit our newly designed web site at
www.alsala.org

FROM THE PRESIDENT...

An introduction from newly-elected board president John Krave

I am the new President of the Chapter, and come to the job with a combination of great optimism and trepidation. I am optimistic because I have the opportunity to build upon the many accomplishments of generous staff, volunteers, Board members and Cecile Falk Balsler, Ph.D., who preceded me as President. Cecile "set the table" for expansion of our Chapter activities, and growth into a mature organization capable of expanding the scope and beneficiaries of our activities. Thankfully, Cecile remains involved in the Chapter, both as a Board member and as a continual source of practical, patient advice.

I have thought long and hard concerning the goals for my term. A single all-encompassing word captures all: **Service**. We are a service organization, dedicated to serving our PALS and their caregivers as they cope with all aspects of ALS. Fortunately, the Chapter is blessed with a dedicated patient services staff who live out this objective every day through direct assistance to PALS in navigating through our often impenetrable health care and insurance systems, equipment loans, and simply caring.

I am not convinced, however, that we are serving all the potential PALS within our service area. Statistics suggest that many more persons suffer from ALS within our service area than we have on our roster of PALS. I am hopeful that the Chapter can make great strides in this area, and determine how we can best serve those ALS patients and their families who may not have heard of the organization and need what we have to offer.

It is indeed a challenging time to take on this assignment. From a financial standpoint, the availability of grants diminished in 2002 as the economy slowed, and there are few signs of a strong rebound in 2003. As a consequence, the Chapter is in need of support through our annual golf tournament, Walk to D'Feet ALS, and other activities that allow participants to enjoy themselves while serving others. We look forward to your support.

The Chapter is also experiencing a change in leadership. Effective March 1, Ray Corvan, our Executive Director, is moving on to other personal challenges. I have enjoyed my interaction with Ray during his tenure, and am grateful for his guidance in any number of areas. We wish him all the best in his future endeavors.




CHAPTER LAUNCHES IMPROVED WEBSITE!

by Jeff Henderson, ALSA Staff Member

At the beginning of 2003, the chapter recognized that the current web site was long outdated, and there was significant potential for providing better services to our PALS, caregivers, volunteers, and donors through an improved web site. Since that time, the staff has been working diligently to develop a world-class site for the Greater Los Angeles area. The primary focus of the web site is on our PALS (PALServices), where we will provide current information about services, seminars, and other ALSA-provided services. Caregivers will also be targeted in the "Caregivers Services" section, where we will highlight some local help for caregivers. Fundraising events will be highlighted, providing on-line event registrations, information, and past event photographs and summaries in the "ALSA Events." Donors will be targeted with our "Donor Services" section, which will provide on-line donation services and other options for our gracious donors. The "Volunteers" section will provide on-line information about the organization's volunteer needs, volunteer applications, and other volunteer information. Our "Media" section will include recent press releases, recent Public Service Announcements (PSAs), and other multimedia that may be of interest to our audience. Finally, the "About the ALSA" section provides details about the organization and those who dedicate their time and energy towards making living with ALS easier for PALS and their families.



PLANS UNDERWAY FOR ADVOCACY TRIP IN MAY!

ALSA's 2003 National ALS Advocacy Day/ Public Policy Conference is the community's only opportunity to join together to educate Members of Congress on the importance of stepping up the fight to conquer ALS through research, care and support. The Greater Los Angeles Chapter has a team of volunteers, PALS and staff who are taking YOUR message to Capital Hill on May 1st. We are asking everyone to please write a letter to your representative asking for increased funding for the development of a drug benefit program for Medicare beneficiaries, and to help implement a program of support for PALS and caregivers. Please forward letters to the Chapter Office for delivery in Washington D.C. Visit our web site at www.alsala.org for samples of letters and representatives names and addresses. If you need any help, please contact the Chapter office.



Yorkin Sinchawla
Santpal Sinchawla

Bill and Marilyn Sousa
Les and Diane Light

Sophie Hoffman
Rhonda Smith

Jeff Weinstein
Mr. and Mrs. Spiegelman
Kerry Underwood
Eva Wolpe

Danny Shikuma
Leo Chavez Family

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web: www.alsala.org



Donations, Memberships and Memorials

The Greater Los Angeles Chapter of The ALS Association is truly grateful for the support we receive. The following acknowledgment lists person and groups who contributed to our organization during the period of November 1, 2002 to February 25, 2003. Through these donations, the Chapter provides a way to remember and pay tribute to those who struggled valiantly in battling ALS. In addition, because of your care and support, we are able to continue providing valuable patient services to individuals with ALS and their families, and to support needed research. Due to space restriction, Walk to D'Feet donations below \$1,000 are not included.

If a family member or friend has died of ALS and you wish to honor their memory, you may, in lieu of flowers, request donations to the Chapter. Please designate in the death notice that donations should be made to The ALS Association, Greater Los Angeles Chapter, P.O. Box 565, Agoura Hills, CA 91376-0565. You may request a supply of tribute envelopes to have on hand at the funeral home by calling (818) 865-8067.

WALK TO D'FEET \$1,000+

Aptan Corpration
Briefly Stated
California Community
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Georgette Dunst
Daniel and Catherine
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Joe and Eva Perez
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Janis Grinnell
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Maralee Harsell
Petra Hayes
Cynthia Hernandez
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Adele Keroack
Barbara Knapp
Abdi and Mina Kolahi
Sam Kozasky
Bernie and Selma Kraft
Barbara Lane
Elmer Larson
Craig and Robin Levra
Sheldon Levy
Macy's - Woodland Hills
Alphonse and Nina

Martorella
Perry and Mona Massey
Donna McClain
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Moskowitz
Shirley Mullen
Cliff and Ninetta Park
JoAnn Penuela
Doris and Shelly Pepper
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Marilyn Powell
Paul and Pauli Powers
William and Marianne Propst
Joseph Ranalette
Susan Rasmussen
Rose Ross
Harvey and Margaret
Saferstein
Fred and Eileen Schoellkopf
Art Schwartz
Lucy Schwartz
Suzanne Segal
Steve and Robbin Sercu
Janet Shute
Pamela Shriver
Sally Somers
Michael and Debbie Stein
Susan Stoker
Dr. Lee Stoltzfus
Debby Stratman
Judy Stuart
Suncork
Jamie Thompson
Gene and Cynthia Torgow
Jeanne Turner - Mimi's Caf e
Judy Uhl
United Way
Roland Vasin - Vasin, Heyn
and Co.
Dr. Verdi
Lisa Whiteaker
Russ Woody
Mary Jane and Thomas
Wright

Yvonne Yanes
Zartab Zafar

DONATIONS: \$500 +

Lawrence and Ida Baker
John Calandri - John
Calandri Farms
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Agency
Carol Econn
Edison International
Jack Harding
Bill and Louise Rice
Rotary Club of Simi Valley
Toyota Motor Sales

GRANTS

Sheila Gold Foundation
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BIRTHDAY TRIBUTES

Joseph Dyrzc
Joy Tanzman

In Honor of
Susan Lurie's Wedding
Jayson and Irma Brodie

Merrill B. Grier
John and Kim Bessolo

Ken Moe
Karen Gailey

Jack Harding
Daniel and Lori Azemar
Gary and Sue Harding

Michael and Stacy Gagner
Dale and Bea Inman

Norma Ramirez
Patrick Jones

Patient Services

A PRIMER ON STEM CELLS

The National ALSA web site is now featuring a spotlight on stem cells. For everything you ever wanted to know about stem cells, click on http://www.alsa.org/research/stem_cells.cfm and you'll be directed to the article.

We encourage you to visit www.alsa.org regularly to keep up-to-date on research findings.

COORDINACIÓN DE SERVICIOS Y AYUDA EN LA COMUNIDAD

Escrito por Pedro Loza



Personas con ALS (PALS) y sus familias estan a menudo sobrecargadas con problemas asociados con el mejoramiento y calidad de vida de familiares luchando con ALS. La Asociación del Cap tulo de Los Angeles de ALS cree que la familia deberia tener libertad en concentrar sus energias disfrutando de su tiempo con familiares y amigos y no estar agobiados con el manejo de asuntos del seguro o investigando los caminos necesarios para el cuidado de la persona con ALS.

Para asistir a las familias con estos asuntos, tenemos el placer de anunciar que la division de coordinaci n de servicios que forma parte de nuestro departamento de servicios a nuestros pacientes esta a su disposici n. Nuestros manajadores de casos son profesionales que estan entrenados para servirle. Para ir directo al problema, pelear por sus derechos y coordinar los servicios para expresar sus necesidades especificas es parte de nuestro trabajo. Mientras que no podemos garantizar los resultados deseados, en nuestros esfuerzos convenidos, haremos todo lo posible para asistir a su familia. Este es un servicio gratis para todos los PALS afiliados con la asociaci n del cap tulo de Los Angeles. Los Manejadores de Casos pueden asisterle en encontrar ayuda en la comunidad como comida, asistencia legal, equipo m dico y la lista sigue. Si uste sufre de esta enfermedad haga el favor de llamar a Pedro Loza, Manejador de Casos, (562) 928-5408 y con gusto le ayudaremos.



Thank you to Dan Borchers (right), our Aventis representative, for all his years of service and friendship to The ALS Association and the UCLA MDA/ALS Clinic. We welcome Tom Baker (left), our new representative, to the area! (Also pictured, Dr. Linda Sepulveda, center)

SPORADIC ALS STUDY

The research team at the Les Turner ALS Laboratory continues to recruit families for a study involving sporadic (or non-inherited) ALS. As the cause of sporadic ALS is unknown, the team is trying to determine whether genetic factors may "predispose" an individual to developing sporadic ALS. In the past, research has looked at cause and effect in sporadic ALS one variable at a time. The team suspects that sporadic ALS may be the result of not one, but several genetic factors coming together. Recent advances in the field of statistical genetics make it possible to answer such questions if there are sufficient study participants available. Blood samples from ALS patients, their living parents and brothers and sisters are needed for this study. The study needs 400 sets of samples from a patient and that patient's parents, of which there are currently 212. Additionally, the study needs 400 sets of samples from a patient and that patient's brother or sister, who is preferably at least as old as the patient was when he or she first noted symptoms of ALS. Currently the study has 299 of those sets. Two tablespoons of blood are needed from each participant. The research team will supply the needed tubes and instructions for returning the samples via Federal Express without charge to the participants. Most physicians and labs will draw the samples without charge, but the study will pay for drawing of samples if applicable.

Obviously there will not be an immediate benefit to patients, but an understanding of the causes of ALS may eventually benefit patients with the disease. If you and your family would be interested in participating, please contact Lisa Dellefave, M.S. at (312) 503-0154 or Nailah Siddique, R.N., M.S.N. at (312) 503-2712. The research team is optimistic that these important discoveries will lead to improved methods of diagnosing ALS and to new treatments and preventive measures.

SUPPORT GROUP SCHEDULE

Westside Group:

American Red Cross Building
VA Grounds, 11355 Ohio Avenue,
Los Angeles, CA 90025
First Saturday of the month, 2 p.m.
Contact: Janet Yamanishi
(310) 316-1626 for topic/speakers

Pasadena:

Lamanda Park Library
140 South Altadena Drive,
Pasadena
Third Saturday of the month, 2 p.m.
Contact: Joyce Lauterback
(818) 421-9729 for topic/speakers

Westlake Village/ Ventura County:

City of Westlake Village Library/
City Hall
Community Room
31200 Oak Crest Drive,
Westlake Village
Fourth Saturday of the month,
1 p.m.
Contact: Joyce Lauterback
(818) 421-9729 for topic/speakers

Spanish Speaking Group:

Contacten: Martha Mowatt
(562) 889-9452 para direccion,
tema y presentador. Se reune
cada tres meses.

NEW CAREGIVER SUPPORT GROUPS ANNOUNCED!

by Ann VerPlanck, MA, Director of Patient Services

As you know, to celebrate National Caregiver's Month last November, the chapter offered a two-hour caregiver group in four different locations throughout LA and Ventura counties. We had good response from those groups and as a result have decided to offer them monthly, in one of those four locations each month. Dillon Woods, the facilitator in November, has graciously offered to volunteer his time to lead the monthly caregiver groups. Our first group was in February in San Gabriel. The March group will be in Westlake Village. Beginning in March and for April, May and June, Ferne Hayes, PT, Director of the Chapter Equipment Loan Pool will be teaching transfer techniques at each of the groups. I just wanted to take this opportunity to make you aware of the groups and invite any of you caregivers who would like a place to share your experiences and get support to attend. For further information, you can contact Dillon directly at: (310) 403-6043. Watch the support group mailings for future group times and locations.



THE POWER OF MUSIC TO SOOTHE THE SOUL

By Michelle Tormey

My name is Michelle Tormey and I am a recent graduate of a program that trains people to play healing music at the bedside.



This program, MHTP started several years ago when a harpist was playing her harp in the intensive care unit where her father lay dying. The staff was amazed to see that as this person played, her father's heart rate steadied, his blood pressure went down, his whole body relaxed and he required less medication for pain. They weren't sure if it was the music, or the fact that it was his child playing, so they asked if she wouldn't mind playing for others in the unit. She complied, and to their amazement, the effects on the others were the same.

A great deal of research has been done on the benefits of music on the mind, body and spirit. Scientifically, it is not known exactly why music has such a profound affect on us, though it has been proven that living cells react to vibrations. It is clear, however, that music has a powerful affect on our emotions. Who hasn't had trouble holding still while listening to music with a strong beat, or becoming meditative during certain sonatas? And who lately hasn't teared up upon hearing the national anthem, or been flooded with nostalgic images while listening to music from their youth? It has been known for centuries that music can soften a furrowed brow or stir soldiers to valiant battle. More research is being done to explain this, but in the meantime, those of us in MHTP continue to provide our services.

On May 17, 2003, I will be playing my harp for you at the "Ask the Experts" symposium Fearless Living with ALS - II. Please come and experience the power of music! My personal CD recommendation for this edition of The Messenger - "State of Grace" produced by Winham Hill. Quite beautiful with lots of "full" sweeping music.

VISIT SUPPORT GROUP LEADER DILLON WOODS WEB SITE

Throughout his life, Dillon has combined his interest in community service and entertainment in a wide variety of ways. He has given hundreds of seminars across the United States and Canada in areas of self-improvement, caregiving, improving communication skills and spirituality. He has composed and produced several albums of music. His latest work is an album entitled *Seasons*. He is presently involved in supporting caregivers, hospices and medical professionals across the country with his two books entitled, *Where Souls Meet: Caring for the seriously ill* and *Questions... for Quiet Times*. For more, see www.livingwithquality.com



LIVING WITH ALS - PART II

by Denise Glass

In the last edition of The Messenger I shared the beginning of my journey as a person diagnosed with ALS. I scheduled a meeting with my family to communicate with them where I am now and where I fear I will be in the future. I needed to ask for their help and encouragement and for all of us to better understand the depth of my support system.

We met in mid-November around my dining room table. Present were my parents, two brothers, a sister and nephew, a brother and sister-in-law, a dear friend who's husband is fiercely battling ALS, my therapist, and my ALSA case manager, Jackie Neff.

My therapist, Candice, welcomed the group and thanked everyone for coming. Jackie Neff gave an ALS overview and explained the disease, its progression and the specific manifestations of bulbar ALS. My friend, Kathy, shared what it's like to be the wife and 24-hour caregiver for someone in the advanced stages of ALS. And then it was my turn.

I shared with everyone that since my diagnosis in August 2001, my speech and swallowing have become worse and that being tired, stressed and upset also affects me greatly. I am so frustrated and embarrassed when I am out in public because of my garbled speech. I sound as if I've been drinking too much, but have no need to tell everyone I meet that I have ALS, when in fact, 99% of the people on the planet have never heard of it. Also, people have a misconception that either I'm mentally retarded or deaf and try to overcompensate when they speak to me so that I will understand them. Sometimes, it's hard not to laugh!

I explained my great fear of choking when I eat. My anger is constantly present as I am robbed of the enjoyment of eating my favorite foods and find myself relying more and more on soft, mushy dishes. How long will I live missing See's candy, chips, nuts, cookies and bubble gum until I finally ask myself "is this worth it"?

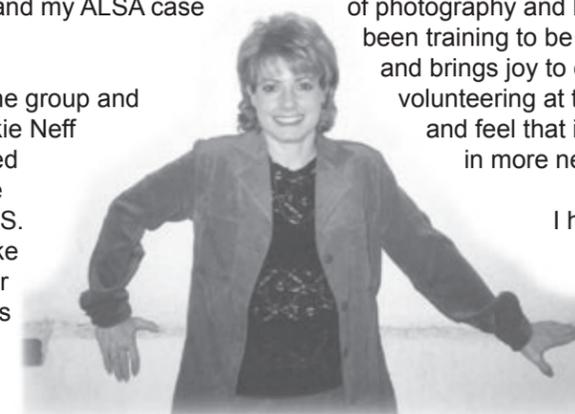
I've learned that when I push myself too hard, trying to accomplish all the things I want to do in my shrinking months and years, I experience great fatigue and have been told over and over again to try to keep my days "flat" - with no great expenditures of physical and emotional energy. But that's not me! Inside I am still Denise, full of life, wanting to play and embrace the "all" of life that I was given.

This thing called "emotional incontinence" is a pain, I told them. I cry at times with no control. Tears flow at all the

wrong and inappropriate times. And another thing, heat now affects me terribly, draining me completely. Oh how I love a cool day with a stiff breeze! Soon the valley heat will be here.

Down the road I'm afraid where the money will come from to care for me and I ask myself should I save for later or simply "go for it" and spend what money I have on accomplishing my dreams. As a single woman I am worried about who will take intimate care of this body. I assured my family that I do not want to be a burden, but in reality, I will be needing care 24-hours a day in the future.

In the meantime, I have some very real goals. I want to go to Antarctica, Europe, ski the Alps, deepen my love of photography and live by the cool ocean. I have also been training to be a clown, a passion that enlivens me and brings joy to others for as long as I can. I enjoy volunteering at the ALS Association L.A. Chapter office and feel that in doing so I am helping those who are in more need than I.



I have asked my family for this: please be gentle with my feelings, but don't patronize me or treat me as a child. I am an adult, and regardless of what the outer looks like, it's still me in here! And when it's my time to go, let me choose how to do so. I will have my Advance Directive in

order, please respect all my wishes.

And now, I must close this article. I'm flying to Las Vegas to attend the Great Clown Adventure Convention at Circus Circus and plan to have a darn good time! I have a lot of living to do and now that I have made everything clear for everyone, including myself, I'm off to make every day my best one ever!

Thank You for Matching the Gifts!

Thank you to the following corporations for matching the generous gifts of their employees:

- American Express Gift Matching Program
- Amgen Foundation
- BP Pensioners/Retirees Matching Gifts Fund
- Capital Group Companies Charitable Foundation
- Charles Schwab Corporation Foundation Employee Matching Gifts Program
- Citigroup Foundation
- Microsoft Matching Gifts Program
- Oracle Matching Gifts
- PFM Matching Gifts
- Reader's Digest Foundation
- Verizon Foundation
- Vulcan Materials Company