

OUR MISSION

To be the central source in the Greater Los Angeles area for services and education for ALS patients, families and caregivers.

ALS is also known as
"Lou Gehrig's Disease"

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The ALS Messenger is published four times annually by the ALS Association, Greater Los Angeles Chapter. The ALS Association is the only non-profit, national voluntary health organization dedicated solely to the fight against Amyotrophic Lateral Sclerosis (Lou Gehrig's Disease) through research, patient support, information dissemination and public awareness.

Walk to D'Feet ALS – One Step at a Time!

by Jamie Thompson



Jamie Thompson and Jenny Craft volunteering at the Walk to D'Feet

What has over 2,000 legs, a coat of many colors, 101 volunteers, an amazing spirit and over \$250,000 in its' pockets? If you answered the Greater Los Angeles Chapter's 2002 Walk to D'Feet ALS team, you were right!

On October 5th, over 1,000 walkers met in Santa Monica's Reed Park to support this year's Walk to D'Feet ALS. Radio host Mark Wallengren (KOST 103.5) kicked things off by welcoming the walkers and thanking them for their participation. He then introduced this year's event co-chairs Peter Pierce, Liz Bluestein and Robert Goldshan, Family Chairs Ken and Marta Moe, executive director Ray Corvan, and the ALSA National Office President and CEO, Mike Havlicek. We were honored that city councilman Richard Bloom presented the Association with a special

proclamation on behalf of the city of Santa Monica, in support of the search for a cure for ALS.

Demetra George, 2002 Grammy Nominee in classical music and former Miss Oklahoma, inspired walkers with her moving rendition of the National Anthem. DJ Brian Pierce then got everyone's hearts pumping with his unique and lively warm-up routine. Who wouldn't be ready to walk after all this fun?



Seventy-five walking teams approached the starting line promptly at 9:30 a.m. As their team names were called out, a cheer was heard around the park. Parading under a red and white balloon arch, they headed down California Avenue carrying signs and banners, eagerly embarking on the 5K walk through the colorful streets of Santa Monica. Dedicated team captains, who had been working for months recruiting walkers and donors, celebrated their accomplishments as they crossed the finish line. Together we have successfully increased awareness of ALS in our community and raised needed funds for patient services and research – and this we did, one team, one walker, one step at a time.

EXECUTIVE DIRECTOR'S REPORT By Ray Corvan



Ray Corvan

The year 2002 is quickly coming to an end, and as I look back over this past year I can recall some very special memories.

First and foremost was the parade of colors displayed by 1100 walkers at our Walk to D'Feet ALS on October 5th. The compassion that

was shown by everyone there has become a memory I will keep with me for a very long time.

The next thing is the wonderful work that was done by the hundreds of volunteers. Thousands of volunteer hours were spent making sure that everything that needed to be done for the chapter was done and it was done with professionalism and pride with an eye for detail.

The next memory is of the faces of the participants at our May "Ask The Experts" program. Everyone in attendance seemed to have a really good time, they seemed to be happy with the information that they received, but also they all seemed genuinely pleased that the information was uplifting and dealt with things that could be fun and exciting. I was pleased that this program was so well received.

Last but not least, as I look back on this year and I remember the mission of our chapter, and I

believe that our patients, persons with ALS (PALS) received the best service we could offer. If we at the chapter continue to keep that goal in mind, we can only get bigger and better and stronger.

To all of you and yours, I hope you have a wonderful holiday season. I hope we will be closer to our ultimate goal of finding a cure for ALS in the very near future.



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'TIS THE SEASON

by Cecile Falk Balser, President

It is that time of year again. The time to receive, by giving. The time to look back, reevaluate and look towards the future. Hopefully we do this all year, but we ceremonialize it at this time of year according to our faiths and beliefs.

In looking back, those of us involved in The Greater Los Angeles Chapter of The ALS Association have a great deal to be appreciative of. We have an organization filled with dedicated and devoted people who take pleasure and pride in improving the lives of PALS and their family members. We have a constituency, you, the PALS and your families and friends, who work shoulder to shoulder with us in each endeavor, helping us to grow and improve.

For myself, I want to personally thank the staff, for they have made our Chapter a working family. I want to thank our volunteers for your hard work and dedication. I want to thank our PALS for both appreciating our service and holding us to task. Last, but not least, I want to thank our Board members for always being



Cecile Falk Balser

willing to be there (and there have been a lot of "theres" this year). From the Chapter, we thank you all for both your generosity and devotion. This enables us to keep going. We promise you that as we look back and reevaluate, anything we implement will be done with the intent of making what is already good, even better. We wish you all a season of happiness and a wonderful New Year

Congratulations to Our Top 20 Fundraising Teams

1. Hard D'Feetors	\$23,630.00
2. Tharnstrom/McCain Family	\$13,385.00
3. Korn/Ferry	\$12,913.00
4. Edmond's Angels	\$12,675.00
5. Burton's Bunch	\$11,024.00
6. Sandy	\$10,598.00
7. 2nd Annual Jeff Weinstein Team	\$10,090.00
8. Dare with Denise	\$9,293.00
9. Suzanne's Supporters	\$8,992.00
10. Dan's Disciples	\$8,898.00
11. Armstrong's Army	\$8,660.00
12. Saul's Angels	\$8,075.00
13. Calabasas Crusaders	\$5,306.00
14. Ken's Krew	\$4,397.00
15. Norma's Nurses	\$4,378.00
16. McMurphy 2002	\$4,090.00
17. Stormin Normin	\$3,752.00
18. Ernie's Force	\$3,669.00
19. Ann's Angels	\$3,646.00
20. Jeannie's Gems	\$3,520.00

Congratulations to the Top Individual Fund Raisers

1. Colleen Hulce with the Korn/Ferry Team
2. Nancy Taylor with Burton's Bunch
3. Denise McCain Tharnstrom with the Tharnstrom/McCain Family Team
4. Henry Lurie with Sandy's Team
5. Denise Glass with the Dare with Denise Team

Top Teams with Registered Walkers

1. Hard Dfeetors	98 Walkers
2. The 2nd Annual Jeff Weinstein Team	85 Walkers
3. Calabasas Crusaders	54 Walkers
4. McMurphy 2002	52 Walker
tied with Suzanne's Supporters	52 Walkers
5. Ann's Angels	49 Walkers



"Calabasas Crusaders"



"Saul's Angels"



"The E Team"



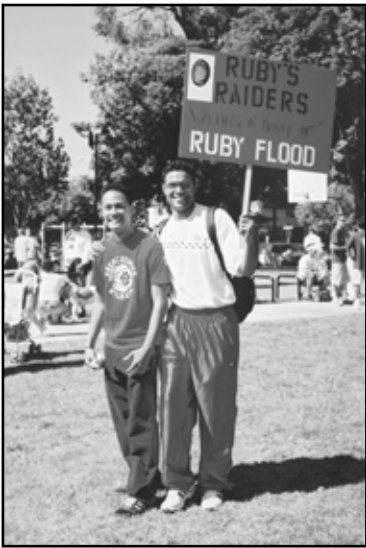
"Team Sandy"



"McMurphy 2002"

Thank You to All Our 2002 Walk to D’Feet ALS Teams

802L (Irvine) walking in honor of Ronald Mills
ago-pica walking in memory of Agop Garabedian
ALS Knockouts walking in honor of all PALS
Andrea Garcia walking in memory of Andrea Garcia
Ann’s Angels walking in honor of Ann Spring
Armstrong’s Army walking in honor of Nadine Armstrong
Bertha’s Angels walking in memory of Bertha Quezada
Binsley Family walking in honor of Bob Binsley
Burton’s Bunch walking in honor of Burton Taylor
BYC walking in memory of Bong Yoon Chey
Calabasas Crusaders walking in honor of all PALS
CART’s Hearts walking in honor of all PALS
Dan’s Disciples walking in memory of Daniel S. Mark
Dan’s Rat Finks walking in honor of Danny Shikuma
Dancers for Dorothy walking in memory of Dorothy Montoya
Dare with Denise walking in honor of Denise Glass
Econn Family Team walking in memory of Richard C. Econn
Edmond’s Angels walking in honor of Edmond Asouline
Ernie’s Force walking in honor of Ernie Wallengren
Forest City walking in honor of David Jones
Fortune’s Faithful walking in honor of Hosea Fortune’
Gil Girls walking in memory of Gil Mesa
Giovanna’s Quest for Gold walking in honor of all PALS
Grandpa Don’s Team walking in honor of Dan Canfield
Hard Dfeetors walking in honor of Gary Hard
Home Respiratory Care walking in honor of all PALS
Huens/Bourn walking in memory of Herbert Huens
Jeannie’s Gems walking in memory of Jeannie Hickok
Jessie’s Team walking in honor of Jessie Angotti
Kennedy’s Kickers walking in memory of Edwin Kennedy
Ken’s Krew walking in honor of Ken Moe
Korn/Ferry walking in honor of David Jones
Lee’s Leapin’ Lizards walking in honor of Lee Howard and in memory of Edward Copan
LMUers walking in honor of all PALS
Lockton Leaders walking in memory of William Morrison
Los Amigos PALS walking in honor of all PALS
M & M’s- Maxine’s Marchers walking in memory of Maxine Robson
Margie walking in honor of Margie Oman
McMurphy 2002 walking in honor of Brian Murphy
Merril Lynch walking in honor of Edmond Asouline
Mike’s Angels walking in memory of Susan Courtright
Milty’s Marchers walking in memory of Milton Safenowitz
Nivlac V walking in memory of Calvin Magness
Norma’s Nurses walking in honor of Perez Ramirez
Odere walking in honor of Ruth Walk
Olga Hernandez walking in honor of Olga Hernandez
Patty’s Team walking in honor of Pat Hayes
Pepperdine University walking in honor of Robert Appleby
Pete’s Pals walking in memory of Peter Pierce, Sr.
Polytechnic walking in memory of Margaret Kul
Rilutek Runners walking in honor of all PALS
Robert and Cheryl Graves walking in memory of Charlotte Gromberg
Rockey’s Rollers walking in honor of all PALS
Ruby’s Raiders walking in memory of Ruby Flood
SALSA walking in honor of Marlene Hall
Sandy walking in memory of Sandy Lurie
Saul’s Angels walking in memory of Saul Tanzman
Sharon’s Feet walking in honor of Sharon Loeffler
Stormin Normin walking in honor of Norma Perez Ramirez
Studio City Postal Team Brown walking in honor of Henri Etta Brown
Suzanne’s Supporters walking in honor of Suzanne Koehring
Team Dora walking in memory of Dora Escamilla
Team Enzer walking in memory of Mel Enzer
Thamstrom/McCain Family walking in honor of Robert McCain
The ‘A’ Team walking in memory of Agnes A’Meer
2nd Annual Jeff Weinstein Team walking in honor of Jeff Weinstein
The Armidas walking in memory of Armida Hammond
The E-Team walking in honor of Ellen Burke
The Kennedy Kickers walking in memory of Edwin Kennedy
The McMinn Marauders walking in memory of Margarita Del Castillo Nikkel
The Rexon Connection walking in honor of Donald Rexon
The Rotary Club of Simi Valley walking in memory of Ken Constable
Troy’s Feet walking in memory of Troy O’Connor
Walk with Cathy & Liz walking in honor of all PALS
Wells Fargo Group walking in honor of all PALS



“Ruby’s Raiders”



“In Honor of Danny Shikuma”



“For my
Oma Jacoba Vanderplas”

Thank You to Our 101 Walk to D’Feet Volunteers for Donating 817 Hours of Energy!
You Are Our Miracle!

2002 WAT Volunteers

Martha Aggazotti
Chuck Alvarez
Luciana Andrade
Ron Ascher
Nicole Ashby
Mark Baker
Joan Becker
Elizabeth Bluestein
Dan Borchers
Joe Briney
Jenna Brummet
Kris Burkett
Breana Cabral
Ray Cardenas
Danette Cardenas
Demi Cardenas
Randy Cardenas
Ryan Cardenas
Kim Collins
Chase Conove
Jimmy Corvan
Jacquie Corvan
Susan Courtright
Jenny Craft
John Dean
Lee Diaz
Carol Econn
Katie Esterline
Michael Field
Brianna Finn
Lory Foitel
Elisabeth Foitel
Valerie Fontaine
Joyce Fortune’
Lindsay Fredrickson
Demetra George
Ali Gibbs
Denise Glass
Robert Golshan
Russel Gottfried
Arnie Greene
Domninque Isselnane
Corie Johnson
Punita Khanna
Kelly Kogler
Selma Kraft
Adam Leibovitch
Kyle Leibovitch
Josh Leibovitch
Leonard Levine
Dick Levitt
Karah Lockman
Pastor Richard McLean

Cathie Messina
Leah Messina
Paul Meyer
Keith Miley
Caryl Mindlin
Tom Mitchell
Jennifer Mosley
Demetra Mustafaoglu
Devran Mustafaoglu
Denise Mustafaoglu
Mike Mustafaoglu
Tony Nader
Al Nweeia
Cathy Ostiller
Holly Padias
Danny Paulson
Cheree’ Petersen
Brian Pierce
Peter Pierce
Ron Ramos
Melanie Ransford
Alison Ring
Kim Robbins
Ellie Runken
Kerrie Sadler
Emily Sadler
Art Salter
Nicole San Filippo
Vito San Filippo
Linda Sherman
Melissa Sierra
Jessica Silver
Raymond Slotkin
Christine Smith
Jennifer Smith
Pat Snyder
Roger Steinbeck
Barb Stevens
Denise Tharnstrom
Jamie Thompson
Michelle Tormey
Rosa Vongchanglor
Ilse Wacker
Rhonda Wade
Mark Wallengren
Don Winett
Susan Yavari
Arlene Williams



Ron Ramos wakes us up with
Don Francisco’s coffee



Singles Helping Others



Volunteers celebrate success



Robert Golshan, John Dean, Kim
Collins, Joyce Fortune’ and
Ellie Runken cheer walkers on.

*Special thanks
to those sponsors
who contributed
so generously
to the*

Walk to D'Feet ALS!

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Back on Broadway



Why Attend a Support Group?

The question “Why do you attend a support group?” was asked at a recent ALS support group meeting?” Here are a few of the responses:

“We think the questions should be ‘Why wouldn’t you want to participate in a support group?’ By attending you will learn from others that have dealt with the various challenges presented by this progressive disease. Each meeting has given us the opportunity to share and learn with others about that journey. We have developed friendships and acquaintances. People in the support group are the only ones that understand what each of us is facing. Why wouldn’t you want to participate in a support group? It eases the burden, and hiding won’t make the struggles go away. Please join us!” Barbara and Carl Frova

“I was diagnosed with ALS in April 2002. I attend the support groups once a month. The group has given my wife and me a lot of support. I’ve met a lot of people with ALS, some are just beginning and others are advanced. It helps me to cope with the illness. I want to thank my support group leader, Joyce Lauterback and Jackie Neff for all their support.” Herb Vasques, PALS

“I think that the support groups have helped our family because we can share all of the things that we are going through, the frustrations and fear as well as the happiness we have for growing so much closer as a family.” Jenny Craft, Family Member

“As an ALS patient I get much support getting to know other fellow sufferers. The fellowship of the ALS support groups is the most valued.” Sharon Loeffler, PALS

Greater Los Angeles Chapter Support Groups

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

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/speaker

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

Spanish Speaking Group

Contacten: Martha Mowatt
562-889-9452 para direccion, tema
y presentador

Living With ALS How Do I Tell Them?

By Denise Glass

My family does not understand about ALS. They do not see by looking at me today where this disease will take me in the next few months or the next year. How do I tell them?

I was diagnosed in August 2001, but I had symptoms for about a year. It started with a slight slurring of my words and a slowing of my speech. I was experiencing choking and extreme fatigue. I knew something was very wrong. I thought I was suffering from stress. When I went to my first neurologist, he told me that all my problems were caused by stress and my symptoms would go away with time. But they didn’t, and I was finally correctly diagnosed at UCLA.

I had witnessed the effects of ALS several years before, when my dear boss, Harry Green, was diagnosed with bulbar ALS. I saw how the disease traveled quickly through his body and how it affected his entire family. Seeing this, knowing what I did about ALS, I was afraid . . . I am afraid. As a single woman, I wonder who will be my safety net when I need ever-increasing care. I wonder how I can communicate to my parents and siblings the devastation of ALS and this path that I find myself traveling down, so they will understand. I have so much to say to my family and realize I have much to share that may be of help to others dealing with the same challenges that I now face.

I have scheduled a family meeting at my house in mid-November. Gathered around my dining room table will be my parents, two brothers, a sister, a niece 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. We will sit and learn together how to help, plan, manage, and cope with my diagnosis, my future, and my today. I will share with Molly Rockey at the Chapter Office what proves to be helpful and useful at this family meeting so that we can best share it with all of you PALS.

(To be continued in the next edition)



“PALS Denise Glass”

Website of Interest - Recommended by PALS David Norwood

Living with ALS E-mail Discussion Group

Type in address <http://groups.yahoo.com/group/living-with-als> and click on “Join This Group”. If you do not already have a free Yahoo account, click on “Sign Up Now”.

This web site is an avenue for PALS and their caregivers to communicate, and to share information, support and fellowship. Moderator is Julie Scurich, OTR. Postings include questions and answers, tips, personal stories and information on research. Note: The ALS Association provides these links for informational purposes only. ALSA does not endorse these Web sites, nor any product or physician represented on the sites.

Volunteers Needed for “Pals for PALS” Home Visiting Program

Training Class

Saturday, January 18, 2003

10 am – 1 pm

Lamanda Park Library

140 South Altadena Drive, Pasadena

Contact Molly Rockey, Director of Volunteer Services

for more information and to register for training

(818) 865-8067 or emrock2000@aol.com

Greater Los Angeles Chapter Resources

Fern Hayes

Equipment Pool Director
(626) 449-0605 • elpferne@aol.com

Linda Madole

Augmentative/Alternative
Communications Director
lindamadole@cox.net

IDEAS FOR HOLIDAY GIVING

by Ferne Hayes, PT

With a variety of end of year holidays approaching, most of us can't avoid the prevailing commercialism.

If you are a person with ALS (PALS), now is the time to hint assertively to your loved ones of some items or activities that would really make you happy. You may want to have this article clipped and leave it strategically around!

If you know a person with ALS, make your gift giving count this year by tailoring it especially to your friend's needs or desires. A person with ALS may have muscular weakness that limits his or her mobility in some way. There are some useful items, which are not covered by health insurance or are not available from the LA chapter's Equipment Loan Program. Speak directly with the person or a close family member to find out whether specific items would be helpful or desirable to the PALS. If you are a close family member or friend, get some advice from a health professional or from an ALSA staff or resource person for appropriate recommendations and resources.

Ideas can range from a simple Pilot Dr. Grip or other fat barrel pen (a weak hand can more easily manage a wide grip) to a power lift seat recliner chair (comfort at the flick of a switch and an assist to standing up.)

Perhaps you can offer services – build a wheelchair access ramp, write letters, cook a meal and clean up afterwards, provide tickets and transportation to a sports or cultural event or bring the party to the PALS home for TV or video viewing.

Your gift may be priceless - a gift of your time, whether a once a year special event or a regular commitment that your PALS can count on – which will let you express a true holiday spirit.

Don't forget the PALS' caregiver! Ensure that any gift to the PALS doesn't create more work for the caregiver. If possible, try to arrange your visits to allow the caregiver some needed time off.

Happy Holidays! Contact Ferne Hayes, PT, Equipment Loan Program coordinator, at 626-449-0605 or elpferne@aol.com to discuss your ideas.

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 persons and groups who contributed to our organization during the period of September 1, 2002, to October 31, 2002. Walk To D'Feet ALS™ not included due to space restrictions. 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.

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, PO 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..

Donations \$1 to \$500

Joseph and Janine Bell
Darren Braverman
Susan Clifford
Community Health Charities
of California
L. David Gomez
Joseph and Janet Kourakis
James O'Keefe
Prudential Securities
Joy Tanzman
United Methodist Church
Of Simi Valley
United Way
United Way of Tri-State
Herbert Vasquez
Florence Waters
David & Nancy Wild

\$500 +

Emmett & Linda Bradley
Clayton School Employees
Edison International
Andrew & Virginia Meyer
In Honor Of
Mrs. Vern Harding
Arlene Pilemier
The Harrison Fam
Joy Tanzman
The Rohemn Fam.
In Memory Of
Mike Daher
George & Janel Khouri
James Datria
Judith Datria
Marsha Farrell
Eva Cohn

Margaret Freidman
Rhoda Harding
Arnold & Jeannette Cohn
Geraldine Hildebrand
Jim & Beverly Willis
Bert Lemelin
Petra Hayes
Laura Marks
Parkview School
Richard Robins
Robert Shute
Kevin & Laura Eastman
Saul Tanzman
Charles T. Folsom
Dorothy Tempkin Ziskind
Louis & Grace Nevell
Membership
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Frances Alvarado
Michael Bowen
Susan Daniels
Idele Deutsch
Joyce Fortune
Helen Franke
Elaine Glassman
Cynthia Green - Getter
Mary & Bill Hepler
Milton Katz
George & Janl Khouri
Joan LaBombard
Florence A. McCall

Covering Al The Bases
Harold Pump Foundation
Golf Tournament Sponsor
Chris Julius Caffè D'Amore

CART's Corner – Rancho Los Amigos National Rehabilitation Center

.... Should I be using AAC? ...

For many PALS, communication becomes progressively more difficult due to weakness in the tongue and mouth muscles as well as decreased respiratory support. As speech gets worse there are other methods of communication that PALS may use. These methods include writing, using gestures, and spelling out messages on an alphabet board or an electronic device. These various methods are referred to as augmentative and alternative communication (AAC) approaches. In other words, they are methods that augment or replace speaking.

When should I start considering using AAC? Here are a few questions you can ask yourself

1. Are family and friends asking me to repeat what I say more often?
2. Am I having difficulty being understood in situations with background noise?
3. Are people asking me to repeat myself when talking on the phone?
4. Are my attempts to speak clearly becoming more effortful and tiring?
5. Do I find myself writing or typing long or important messages ahead of time, rather than trying to speak them, because I am afraid people may not understand me?
6. Am I avoiding social and group situations because my speech isn't always clear?

What are the benefits to using AAC?

- People are able to understand what you are trying to say
- Communicating becomes easier and less effortful.
- You are able to communicate your own thoughts and less dependent on family to communicate for you
- You have more success communicating on the telephone

How can I get help?

Contact Linda Madole, ALSA Director of Augmentative Communication

At (310) 874-3934. Request an evaluation by speech/language pathologist who can help determine what types of AAC are best for you.

By Carlene MacBride, Molly Doyle and Barb Phillips CART- Rancho Los Amigos National Rehabilitation Center. 562-401-6800.

www.rancho.org/cart



The Amyotrophic Lateral Sclerosis Association
Greater Los Angeles Chapter
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Do You Have a Simple Wish?

Would you like a volunteer to help you complete a meaningful task? Something that when finished would help you feel more at peace and that a volunteer could complete in about three hours.

Here are some ideas from recently completed Simple Wishes:

- Wrapping holiday gifts
- Placing photos in a memory book
- Making contact with a long lost friend
- Hand writing a letter to someone special
- Cleaning out a cluttered closet
- Organizing poems or recipes into a lovely book

PALS, if you have a Simple Wish idea, simply contact Molly Rockey at the Chapter office at 818-865-8067 or emrock2000@aol.com and we'll make your Simple Wish come true.

Save the Dates!

March 15, 2003

The H.P. and Sophia Taubman Foundation presents:
Ask the Experts for Healthcare Professionals
Doubletree, Santa Monica

May 1, 2003

Advocacy Day in Washington D.C.

May 17, 2003

The H.P. and Sophia Taubman Foundation presents
Ask the Experts, Doubletree Santa Monica
Golf Tournament, North Ranch Country Club

July 21, 2003

October 4, 2003

Walk to D'Feet ALS, Reed Park, Santa Monica