

**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.*

**Papa: A Success Story**

*By Dr. Mona Khanna*

Several years ago when Papa told me that during his 1995 trip to our native India, a prophet had told him that he would die when he was 69 years old, I scoffed. After all, I pointed out, he had always been in the best of health - and he was as robust and active at that time at age 63 as he had ever been. But although I placed no stock in the prophecy, Papa was deeply disturbed at the thought of a date with death.

Then in 1997 at age 65, Papa began to experience difficulty walking, accompanied by a left foot drop. The medical work-up began and two years later he was diagnosed with ALS. How cruelly ironic was that? He and Mom had reared four children in Chicago - three of whom were physicians - and Papa fell prey to a disease that, despite our collective decades of medical training, there existed no cure.

My father, Tilak Raj Khanna, immigrated to the United States in 1965 only days after I was born. The family joke is that I turned out to be the rebel child simply because he wasn't around to rein in my predisposition toward defiance at an early age. Mom, my older sister, older brother and I joined Papa in Chicago after he had completed his master's degree in engineering and secured a residence and job. Like many immigrants, their original plan was to earn money in the U.S. - the "land of opportunity" - and then return to India. But they were soon seduced by the comparatively high standard of living and educational opportunities for their children. Papa found a home for his entrepreneurial spirit and started a side business of importing goods from India in addition to his job as a highway engineer for Cook County. Over the past four years, Papa's health has progres-



*Dr. Mona Khanna and her parents, Tilak Raj and Harita Khanna, celebrate in traditional Indian dress in Chicago in 2000.*

sively deteriorated; predictably, given his ALS diagnosis. The challenge that I faced as a child in trying to keep up with the great strides of his long legs has been replaced with the challenge of trying to avoid bumping his long legs on doorjamb and walls as I maneuver his wheelchair through rooms in our house. The days that I used to step away from him fearing I would deafen at his loud, commanding voice have been replaced by my leaning my head close to his so that I can hear what he is trying to say, as his mouth moves and barely a whisper comes out. The man who, with \$8 in his pocket, forged a life for himself and his family in a foreign country, now needs ADL assistance. Yet his appetite remains voracious and he takes great pride in the continual triumphs of his children.

In honor of Papa and some of his qualities that I inherited - boundless energy, stamina, benevolence and a pathless-traveled frame of mind - I ran the Los Angeles Marathon on March 3. Together with the generous financial and moral support from friends and family, we raised almost \$2,500 for ALSA.

Papa will be 70 years old on September 20, 2002.

## EXECUTIVE DIRECTOR'S REPORT By Ray Corvan



I would like to take these few minutes to highlight some things that are going on around our chapter that may have gone unnoticed by those who are not intimately involved with our day-to-day operations.

In early January 2002, Mr. Dean Rasmussen, got this chapter started on a fund raising event with the Sporting Clays community. This was an area the chapter had never before dealt with. For the next three plus months Dean and Giovanna D'Angelo, our Director of Special Events, worked diligently on this event and on Saturday April 13, 2002 the Sporting Clays Event was held. I must say this was one of the best and smoothest run events I have ever been involved with. This event netted approximately \$35,000 for The ALS Association.

Not only did this event bring in much needed funds for our chapter and ALS research, it also brought our name before a community that until this time may not have known much about us.

Dean Rasmussen has been a good and loyal supporter of this chapter for many, many years, and I wanted to publicly thank him and his family for all their hard work on our behalf.

I would also like to thank our Board of Trustees. As I look at the events our chapter has scheduled for the next twelve months, I see our golf tournament chaired by George Powlick, our Walk to D'Feet ALS chaired by Peter Pierce, and each and every committee chaired by board members. This Association is extremely fortunate to have such dedicated members. There has not been one instance where I have asked for help and have been turned down. All too frequently the hours and hours of work by board members goes unnoticed.

And last but clearly not least, is the work of our hundreds of volunteers. Men and women, boys and girls, who give of their time, not for mone-

tary rewards, not even for the recognition they so rightfully deserve. They do the work out of the goodness of their hearts just because the work needs to be done.

With a team composed of this staff, Board of Trustees and volunteers, the sky is the limit to where we can go. Please, get on board; it's going to be a great ride.



### BOARD OF TRUSTEES

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## FROM THE PRESIDENT By Cecile Falk Balsler

John Jones, M.F.T. and leader of our Pasadena and West Los Angeles support groups will be leaving his position as support group leader. John has worked with the Chapter successfully for many years. He is very dedicated to working with PALS and their families and has been successful in creating groups that are well attended and cohesive. John has been a real advocate for the needs of PALS.

While he will be sorely missed by everyone, John is leaving to expand his private practice and will still maintain an association with our chapter. We hope to be a resource for each other. John will be someone in the community that we can refer to and he will be using the chapter services when appropriate. We wish him well and thank him for all his years of dedicated service.

# Letting Go of the Outcome

## Joyce Lauterback, MFT

Support Group Leader for  
Ventura County and Pasadena

Life is full of surprising twists and turns. We often get into a mindset that dictates how we think things are "supposed to be." If "A" happens then "B" is sure to follow.

Certainly being diagnosed with ALS is a surprising turn that no one expects to take. It is important to let go of the "B" that you think will follow. It is important to keep the door open to positive, unexpected, possibilities.

Perhaps a neighbor you don't know very well becomes a supportive and helpful friend. Maybe a feuding family member chooses reconciliation. Perhaps you get the dog of your dreams in the form of a canine companion. Maybe you no longer put off travel.

In every experience in life there are opportunities to learn new things about oneself. What are the positive, unexpected changes in you? Have you become more patient with yourself or others? Less controlling? More assertive? More truthful? Less stubborn? More interdependent?

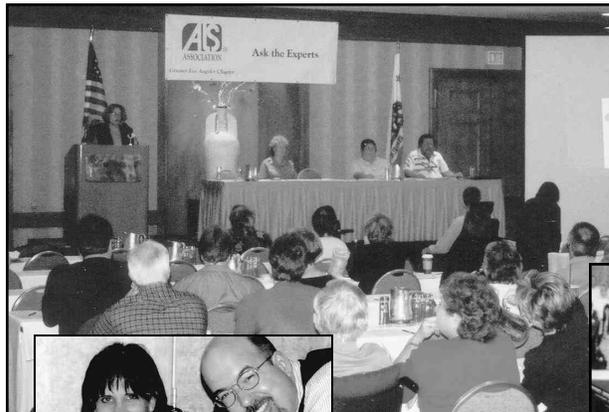
The paradox is that one must surrender rather than seek out or expect a certain outcome. For example: You are sitting by a window and you glance outside to see a beautiful hummingbird flitting from blossom to blossom. It is an unexpected gift in your day. You couldn't plan it. You couldn't look at your clock and say, "In 5 minutes there will be a hummingbird outside." You couldn't sit all day with your jaw clenched and say, "I expect to see a hummingbird. Where is it?!"

Instead, while you were not thinking about a hummingbird at all, in the precise moment you glance out the window there it is! A moment sooner or a moment later, you would never have seen it. Some spiritual or philosophical beliefs consider this being in the moment, letting go of the outcome.

Our own expected outcome is so limited by our preconceived ideas, fears, limited knowledge and other's belief systems. Allow yourself to surrender to divine guidance, spiritual faith or whatever words are comfortable for you. The outcome will be much more expansive than any you could have created for yourself.

# Ask the Experts

Thank You to The Herman P. and Sophia Taubman Foundation for presenting Fearless Living with ALS An Ask the Experts Program, May 4, 2002

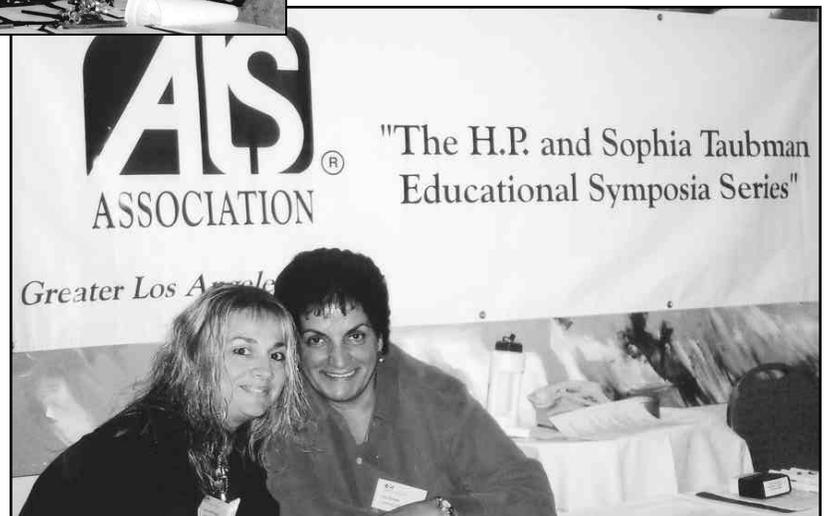
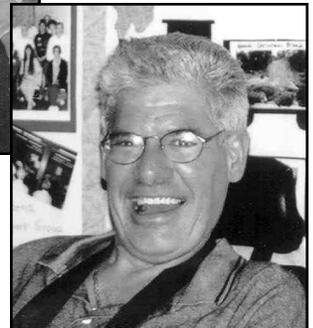


Dr. Linda Sepulveda offers a warm welcome to everyone

Jeff Weinstein sharing a smile



Signing letters to take to Washington D.C.



Joan SanFilippo and Ellie Runken working registration desk



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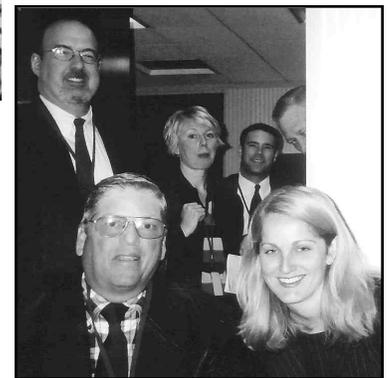
# Advocacy Day Success!

Jennifer Burkhart, Molly Rockey,  
Congresswoman Lois Capps and Peter Pierce,

Thank you to our 2002 Advocacy Day Team who walked the streets and corridors of Capitol Hill in Washington DC on May 16th, telling PALS's stories, requesting support and educating our elected officials. Team members were Los Angeles ALSA Board of Trustee members John Krave and Peter Pierce, Jennifer Burkhart, Director of Patient Social Services with the ALSA National Office, Dr. Linda Sepulveda from the MDA ALS Clinic at UCLA and staff members Ray Corvan, Giovanna D'Angelo

and Molly Rockey. The day started with breakfast with Senator Diane Feinstein and contingencies from all the California ALSA chapters, followed by appointments in the offices of Representatives Lois Capps, Jane Harmon, Adam Schiff, David Dreier, Brad Sherman, Howard Berman, Elton Gallegly, Bill Thomas, Henry Waxman, Maxine Waters, Hilda Solis, Xavier Bacerra and Bud McKeon.

Focus of all meetings: increased spending by the National Institute of Health for ALS research, support of Senate bill S2489, the Lifespan Respite Care Act of 2002, funding through the Department of Defense for research on Gulf War Veterans and Kelly Air



Peter Pierce and Jim Porter, greeted by Senator Diane Feinstein's Legislative Assistant, Charity Bracy

Force Base personnel who have been diagnosed with ALS and lastly, support for a Medicare Prescription Drug Benefit.



2002 Advocacy Day Team, left to right, Ray Corvan, Jennifer Burkhart, John Krave, Molly Rockey, Peter Pierce, Giovanna D'Angelo

## Ann Ver Planck, MA Patient Services Director

Our support groups provide guests who speak on relevant topics to PALS and their families. Also, every group provides the opportunity for attendees to discuss their individual situations and use the group as a problem solving resource.

In my role as Patient Services Director, I've been thinking about other kinds of groups that people might find helpful. Two that come to mind are caregiver support groups and bereavement support groups. Call or e-mail me to let me know if you would attend these kinds of groups. Or, give me an idea of other groups you might like to see the Chapter develop. You can reach me at: 562-981-1678 or can send me an email at: ALSAnnVP@aol.com.

For Those of You Who Have Asked . . . Harpist Michele Tormey Recommends the CD **"On Wings of a Dove - Harp Music to Soothe the Soul"**

Order Now at [www.harpspirit.com](http://www.harpspirit.com)

**25% of all our sales to benefit ALS Association,  
Greater LA Chapter Thank You, Michele!**

## Why Cook?

**Celebrates 10 Years  
of Success with  
ALSA Fundraiser!**

Thank you Arina and Breana Cabral for hosting an exciting fundraiser May 19th at Moomba restaurant in West Hollywood. Proceeds have been donated to the Chapter in memory of Breana's father, Troy O'Connor, who was diagnosed with ALS in 1994.

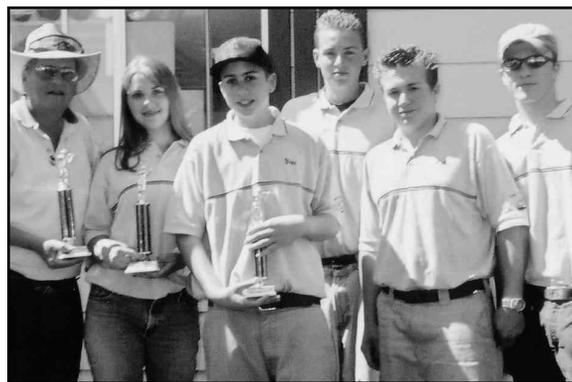
# Shooting Down ALS *By Lori E. Porter*

On Saturday, April 13th, one of the warmest and radiant days so far this year, the ALS Association, Greater Los Angeles Chapter, held their first Sporting Clays Tournament in San Fernando at Moore-N-Moore Sporting clays. Jim Porter, the day's special honoree, who has a strong enthusiasm for the sport of clay shooting was diagnosed with Amyotrophic Lateral Sclerosis in 1995 and was only given six months to a year to live. Seven years later, on this sunny California spring day, he was there along with 93 shooters who participated in the gunning down of ALS. The morning started off

at 8:00 am with registration and a Continental Breakfast hosted by Cooke's Family Market. There was a Safety Rule Presentation, followed by a practice session and then at 9:00 am the Shotgun Start. With every shot fired that day, and there were many, another gouge was made in the body of this devastating disease.

The team that won first place at the event was that of Priscilla Sutton, Broc Khyn (team captain and All-American in Sporting Clays), Ben Courtemarache, Kyl Frasure (All-American, and Kent Vail (All-American and Junior Olympic Gold Medalist).

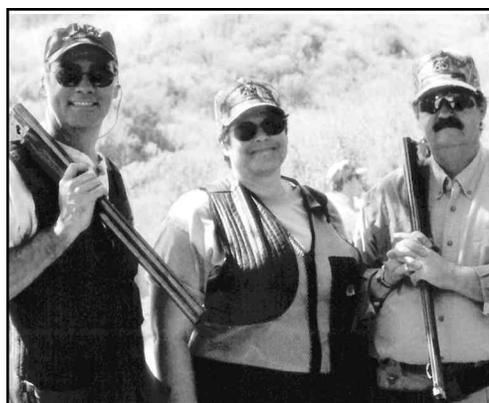
The money raised at this event will support the Lou Gehrig Challenge which funds cutting edge research that will find a cure for ALS. \$20,000 was raised toward patient services and another \$20,000 towards research.



*Sporting Clays 1st Place Team with Jim Porter*



*Dean Rasmussen - Platinum Sponsor*



*Hold Your Fire!*



*Jim Porter receiving award from Pat Moore of Moore-N-Moore Sporting Clays*

## ALSA - LA CHAPTER SUPPORT GROUPS

### **Westside Group:**

American Red Cross Building,  
VA Grounds, 11355 Ohio Avenue,  
Los Angeles, CA 90025  
Meeting Room 7, First Saturday  
of the month, 2:00 p.m.

### **July**

Contact Janet Yamanishi,  
310-316-1626 for topic/speaker

### **August**

Speaker, Molly Rockey, Director of  
Volunteer Services, ALSA GLAC Topic:  
Volunteer Services at Your Service

### **September**

Speaker: Linda Squires-Connor,  
LCSW-Cedars-Sinai Hospital  
Topic- Resources.

### **Westlake Village - Ventura County:**

### **July, August, September**

Contact Joyce Lauterback, 818-421-9729  
for location/speakers/topics

### **Pasadena:**

Lamanda Park Library  
140 South Altadena Dr., Pasadena  
Third Saturday of each  
month at 2:00 p.m.

Contact Joyce Lauterback,  
818-421-9729  
for speakers/topics

### **Spanish-speaking:**

Clifton M. Brakensiek Public Library  
Biblioteca Publica  
Clifton M. Brakensief  
9945 East Flower Street,  
Bellflower, CA  
Third Saturday of each  
month at 3:30 p.m.

Tercer sabado del mes - 3:30 p.m.  
Contacten a Martha Mowatt, 562-889-  
9452 para lectores y temas

# Another Simple Wish Granted

By: Shawn C. Phipps, OTR  
Occupational Therapist  
Rancho Los Amigos National  
Rehabilitation Center

I had the privilege of participating in the Simple Wishes program, sponsored by the Greater Los Angeles Chapter of the ALS Association. This program is designed to pair an Occupational Therapist with a Person with ALS (PALS) and assist them in completing a simple wish that enhances their quality of life.

I was paired with Morris Schwartzman, an actor, choreographer, dancer, and entrepreneur. I first met with Morris in March 2001 and he had been living with ALS since June 2000. He had just recently moved back to his home in the Hollywood Hills with a caregiver after living in a board-and-care facility for several months. During our first meeting together, I discovered that Morris was an extremely talented man that had devoted his personal and professional life to ballroom dancing and acting. He also had a knack for entrepreneurial endeavors, and had managed many businesses on the side. After being diagnosed with ALS, Morris was bed-bound and not able to perform even the most basic of life functions. However, Morris remained full of life and very eloquently described to me his life story in great detail. As Morris' story unfolded, I discovered that Morris had come to terms with his mortality and wanted to leave a piece of himself to his family and friends. His "simple" Wish was to leave behind a legacy of his personal and professional achievements through a video medium. Morris had boxes of videotapes and photographs from various films, commercials, and television shows he had appeared in, but was frustrated that all of the video clips were on different videotapes. Morris' Simple Wish was to organize the various photographs and videos of his personal and career achievements onto a single video that he could give to his closest family and friends.

After he stated his Simple Wish, I immediately thought of an old professor of mine at the University of Southern

## Cart Corner

### *A New and Exciting Loan Program for the LA*

*Chapter By Barb Phillips, MS OTR*

The LA Chapter is taking on yet another new and exciting loan program for PALS ! By June of this year, we should have a variety of different EADL equipment available for loan to the PALS. What is EADL? It is an acronym for Electronic Aids to Daily Living - just a fancy way of saying remote controls.

There are many different types of EADLs that are available for persons who have difficulty, or are unable to operate the little buttons on their remote controls. Others may have problems controlling lights or other simple appliances. Of particular concern are those individuals whose voice is not strong enough to call for help. EADL's provide access to battery or electronically operated devices in the environment.

Why do people use EADL's? They are convenient, they help to conserve energy, they provide independence and improved quality of life and they also reduce attendant care. If your care provider is busy, how wonderful to be able to

California when I was studying to become an Occupational Therapist. Her name was Julie McLaughlin-Gray and her husband, Philip Gray, was a videographer. I e-mailed her right away, and the response was very positive. Philip was very interested in assisting in the project, as he held an interest in telling life stories through videography for persons with disabilities. Together, Phil and I met with Morris to determine the direction of the project, and Morris provided us with photographs and videotapes of his work. Unfortunately, this meeting would be our last with Morris, as he passed away in April of 2001. I honestly believe that Morris was able to rest after knowing that his Simple Wish would be granted.

Over the course of a year, Philip Gray and I edited and created the video tribute to Morris and his family. Morris was of the Jewish faith, and one year after his death, his family held a traditional unveiling ceremony at his gravesite. I met with his closest family and friends as we celebrated Morris' life. We then gathered at Morris'

change the television channels or your CD player by yourself. What if you are watching television, and it starts getting dark? Wouldn't you like to turn on a light? Don't forget the alerting systems - how often have you lied awake at night calling and calling before someone heard you?

EADL's send transmission through the air to devices that are either controlled via radio or infrared beams. Some EADL's control one device, while others control several devices with several functions. An assessment will determine which device will work best for you.

If you think you need an assessment or would like to borrow an EADL, contact Linda Madole, Director of Augmentative Communication, at (310)514-8228, or Ferne Hayes, Patient Liaison at (626) 449-0605.

This program was made possible by donations celebrating Barb's wedding and in memory of her father, Peter Weintraub who lost the battle with ALS on April 21, 1997.

Barb Phillips is an Occupational Therapist working at the Center for Applied Rehabilitation Technology (CART) at Rancho Los Amigos National Rehabilitation Center in Downey, California: (562) 401-6800.

nephew's home to showcase the video, and the response I received from his family and friends was by far one of the most rewarding life experiences. As they viewed the video, Morris' family and friends had the opportunity to reflect on his personal and professional achievements and forever remember the remarkable imprint that his life had on the individuals he loved the most.

In my work as an Occupational Therapist, I am accustomed to understanding the life story and the effects of disability on functional abilities and quality of life. However, this experience allowed me the unforgettable opportunity to provide a humanitarian service to an individual on a much more intimate and powerful level. I feel fortunate to have had the opportunity to know Morris for the short time we spent together and to contribute positively to his quality of life in his final days. I also realized the power of the visual medium in communicating the meaning of one's life. More importantly, Morris' Wish was realized and his family and friends now have a piece of Morris to hold onto forever.

# Joined at the Heart... *by Molly Rockey, Director of Volunteer Services*

There's a delightful little book that was given to me by one of our dear volunteers, Marilyn Way. It's called *Joined at the Heart - A Celebration of Friendship*, and it's full of uplifting quotes beautifully illustrated by Debbie Mumm. Sometimes I take a moment and wander through its pages, looking for a lift or a bit of inspiration. But when this little book is not at hand or in the rush of busy days when there is no time to "wander", I know I can always turn to our volunteers to energize and inspire me, and to remind all of us to make every day special and productive.

Thank you to the following people who have contributed so beautifully over the past three months by sharing their time and talents with us: From Pepperdine University - Jeff Henderson, Patrick Schenner, Carlos Fernandez, Mandeep Sing Kakar, Elsa Peralta and Baris Emiroglu for their work on our golf tournament, Lindsay Blanchard and Mike De Leon for working on press kits, Lisa Strain and Angela Coury for their community outreach work. And especially our American Humanics intern, Maria Caraballo. Thank you Maria, and congratulations on your graduation. We will miss you!

Thank you Pat Snyder for your constant and excellent work at keeping us all updated on ALS research and tips for daily living. Thanks Frank Welch for being our web master. Barbara and Carl Frova, The National Charity League, Shawn Phipps and Phillip Gray for their gifts to the Simple Wishes program. Luciana Andrade and Susan Yavari for their continuous office support. Susan Gardner for sharing her graphic artist talents.

Music Practitioner Intern Michelle Tormey for sharing her harp and gentle spirit with us. UPS Neighbor to Neighbor volunteers who helped with set-up at Ask the Experts. The RSVP Center volunteers at the Goebel Senior Center and Louise and Jackie for helping us organize the work we bring to them. Sarah Kozal for folding newsletters for six hours. Sporting Clay volunteers from UPS - Robert Mosley, Margie Gonzalez, Eden Gerstein, Scott Edwards and Phil Griego. From Pepperdine - Maria Caraballo, Lori Porter, Adam Roche, Celia Haight and her friend Hillary, Plus Aimee Toomey, Nicole SanFilippo, Grace Anderson, Luciana Andrade, Michele Willer-Allred and Jo Ann King. And especially the Rasmussen



*Volunteers from Pepperdine University & UPS Neighbor to Neighbor Program*



*Pepperdine American Humanics Volunteers*

family - Dean, Kathleen, Eric, Charles and Andrew - for there would not have been a sporting clay event without them.

National Charity League volunteers Aileen Hagy, Carolin Kunze, Kathy and Leah Messina, Amy Johnson, Adrana Dhir, Jill Hall, Gail and Anne Marie Boskovich, Helga and Steffi Kupper, Marisa and Geoffrey Loo, Julie Paris, Lauren Hall, Colleen Sheller, Jenna Brummett folded thousands of newsletters.

Thank you to our Board of Trustees, Equipment Loan Pool volunteers, golf tournament and and Walk to D'feet ALS committees who are doing extraordinary work for us - we'll name all of you in the next edition.

Poet Robert Frost points out why the people who come and give so generously of themselves are special - "There never was any heart truly great and generous that was not also tender and compassionate". Thank you volunteers for all your tender and compassionate work, and for your willingness to be "joined at the heart" with each of us at the Greater Los Angeles Chapter.



*You're never too young to volunteer: Vito (12), Olivia (5), Marco (10), Anton (9) SanFilippo*

## Swing Charity Golf Tournament

On Monday, July 22, 2002, our chapter will be hosting its second annual "2002 Authentic Swing Charity Golf Tournament" at the North Ranch Country Club to support the Association's direct patient services for people with ALS. This is a chance to play a great golf course, enjoy fun and friendship, participate in several contests and skills, eat three excellent meals, participate in silent and live auctions, and contribute to a very worthy cause.

We would like to urge you to consider becoming a tournament sponsor. The funds provided by last year's sponsors put our chapter over the top in our fundraising program.

This year our goal is even more ambitious. Your sponsorship of this event will help make a positive impact.

For more information on becoming a sponsor, participating, donation of a silent or live auction item, please call Giovanna D'Angelo, Director of Special Events at (818) 865-8067.



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Greater Los Angeles Chapter  
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## SAVE THE DATE!

### Golf Tournament

North Ranch Country Club  
Monday, July 22, 2002

### Walk to D'Feet ALS

Reed Park, Santa Monica  
Saturday, October 5, 2002

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Chapter at (818) 865-8067.

## We Keep on Moving!

Upcoming Walk to D'Feet ALS  
Until we find a cure — we need your help!

**Saturday, October 5, 2002**

**Reed Park, Santa Monica**

**California Avenue & 7th Street**

Registration begins at 8:30 AM, and the  
walk will begin at 9:30 AM.

For more information, please call,  
Giovanna D'Angelo,

Director of Special Events (818)865-8067.

Visit our website at [www.alsala.org](http://www.alsala.org)

