



**Ernie Wallengren Memorial Basketball Hoop Fest
Raising Funds for The Lou Gehrig Challenge**

On Saturday November 8th, more than 120 basketball players gathered at Calabasas High School to honor and remember a dear friend: Ernie Wallengren. Ernie was a pillar of the Calabasas community while coaching a local club basketball team and the junior varsity basketball team at Calabasas High School for the 2000-2001 season. It was during that time that Ernie was diagnosed with ALS.

On this special Saturday players and guests enjoyed food, fun, camaraderie, a silent auction and of course, hoops. Local officials donated their time and refereed 28 games throughout the day. The entire CHS boys' basketball program provided the manual labor and more than \$18,000 dollars was raised for the Lou Gehrig Challenge ALS research fund. It was a tremendous day for everyone and due to its great success will now become an annual event.

Basketball Fest planners L to R: Alica Gabler, Chris Goode, Lisa Sapiro, Linda Schatz, Mary Jo Ammon, Cheryl Wallengren and Coach Russel White

Walk to D'Feet Special Highlight



Shirley Barondess was easily the oldest walker to participate in the Los Angeles Walk to D'Feet ALS on October 4, 2003. At 90 years young, Shirley was not to be daunted by a mere 5 kilometers. Last year, at 89, she surprised us all. This year, she did it again. Having lost both her husband and her daughter to ALS, Shirley shares her strength with those around her -- and continues to be an inspiration to all of the walkers on Team Sandy. Pictured here with her son-in-law, Henry Lurie, Shirley walks in memory of Sam Barondess and Sandy Lurie.



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

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Volume 4, 2003

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.

Save the Date!

February 19, 2004

Chapter Annual Meeting - 6:00pm
American Red Cross
West Los Angeles

March 11-15, 2004

National ALSA Leadership Conference
Warner Center Marriott, Woodland Hills

March 27, 2004

Ask the Experts for Healthcare Professionals, Doubletree Guest Suites
Santa Monica

May 8, 2004

Ask the Experts for PALS, Families and Friends, Renaissance Los Angeles Hotel at LAX

May 13, 2004

A Time to Care Gala at the Playboy Mansion

May 16 - May 18, 2004

National ALS Advocacy Day/Public Policy Conference, Washington Plaza Hotel
Washington, DC

Watch for These Events

Spring - Walk to D'Feet ALS

San Bernardino

July - Golf at North Ranch Country Club

October - Walk to D'Feet ALS

Santa Monica

MESSENGER

THE ALS ASSOCIATION, GREATER LOS ANGELES CHAPTER SERVING
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My Amazing Son, Gabe!

by Kim Devorris

When Gabe and I first discussed doing the Walk to D'Feet ALS as his Bar Mitzvah project, I had my concerns. Having been diagnosed with ALS just months before, I worried that the project would be a little too close to home for a 12 year old boy to take on. But I also knew how proactive Gabe had been up until this point, from buying me flowers at his department store of choice (7-11) to making me "I love you" cards on the computer. So I thought he might see this as an opportunity to do something to help. He didn't surprise me and jumped at the chance to form our walking team - "Kim's Walk and Rollers". With the help of my dear friends Sherrie Goldfarb, Barbara Shifren and Aline Smithson and their families, Gabe was able to organize the entire event including writing a heartfelt appeal letter for donations and walkers, getting the letters stuffed and mailed, keeping track of the incredible amount of responses that came in and being an energetic, spirited and supportive Team Captain. What did surprise me was the response he received from his appeal letter. The concern, support and generosity that came from my family and friends was just overwhelming! I am truly the luckiest woman in the world to be surrounded by such a loving and giving group of people, especially . . .

MY AMAZING SON, GABE!



Kim and Gabe surrounded by "Kim's Walk and Rollers"

ALSA Greater Los Angeles Chapter News

Lou Gehrig Walked 1,508 Times for His Team... Won't You Walk Once for Ours?

By Fred Fisher, Executive Director



This was the question and you answered the call. Walkers, supporters and volunteers alike turned out in record numbers to make this years walk the most successful in Chapter history and among the largest in the country.

Like magic, the weather turned from a week of clouds and drizzle to bright blue sunshine, just in time to welcome everyone to Santa Monica. But the weather was just the beginning of the magic as volunteers arrived and transformed the park into a gathering place to celebrate life and the search for a cure for ALS.

However, this magical day was not the result of the wave of a wand. The magic happened through the will and determination of staff, volunteers, families and friends joined together for a single purpose. The outreach was phenomenal as more than 2,000 friends from across Southern California gathered in a show of solidarity and support for those who are in the fight of their lives.

Those who could not join us at the park added their voice to the more than 4,000 contributors who together raised more than \$370,000 in support of patient service programs, advocacy and the search for a cure.

On behalf of the Board of Directors, staff, volunteers and the families we serve everyday, thank you for answering our call.

ALS ASSOCIATION

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The ALS Association of Greater Los Angeles
 P.O. Box 565, Agoura Hills, CA 91376-0565
 Phone: (818) 865-8067 / fax: (818) 865-8066
 Email: info@alsala.org • Web: www.alsala.org

Support Group Schedule

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

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

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

Donations, Memberships and Memorials

We gratefully acknowledge the following people and groups who generously made memorial gifts and contributions to our chapter between August 15 and October 31, 2004. Monies received support patient services, advocacy, public awareness and research into the causes and a cure for ALS. Upon receipt of these gifts, an acknowledgement of the gift is sent to the person or family designated. All contributions are tax deductible. Due to space restrictions Walk to D'Feet ALS are not included

Donations over \$500

Sylvia Fritz

Dance for Life

N. Hollywood Church of Religious Science

Matching Gifts

Clayton School Employees Foundation

Rasmussen Challenge

Emily Bresler
 Peter Pierce

Grant in memory of Ernie Wallengren

Aaroe Associates of Charitable Foundation

Donations \$0 to \$500

Kenneth and Charlotte Gromberg

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Elaine Steinberg

Employee Contributions Campaign

Franklin D. Arbogast

G & G Fritzing Living Trust

Gail Shultz and Bob McClatcher

Glen and Joyce Isomoto

Guadalupe Arredondo

Harvey and Esther Olifson

Heidi Freeman

Mark and Peachy Levy

Miles and Camilla Perlis

Paige Schenker

Robert L. Shapiro

Susan Maydeck

Dance for Life

Antoinett and Thomas Sexton

Ashleigh Harris

Joy Harris

Kathy Velasco

Marla Dahbura

Nancy and Glen Yokoe

Patricia Jo Harris

In Memory of

Carl Frava

Elsie and Frank Witman

Gloria Dramis

John and Charlotte Berra

Dorothy George

David and Marion Laccisano

David D. Laccisano

Deanna and Josip Palic

Emmy Georges

James Murodacco M.D.

Mary Alice Laccisano and Deborah Keith

Pat and Susan Murodacco

Trevor Hambrook

Barbara Frava

Family of Trevor Hambrook

Phyllis Hilts

Jessie J. Duffy

Helen Brooks Fund

Diana McCormac

Rita Sloan

Heartwell Womens Golf Club

Bettie and Herbert Grimm

Gavino Valles

Marcia Valles

Jack Harding

Amy and James Macklin

Arnold and Jeannette Cohn

Charles and Lorna Reed

Dan and Mary Lou Hedrick

Daniel and Gay Place

Daniel and Lori Azemar

Doris and Robert Coates

Elaine Clippinger

Eloise Caldwell

Gary and Claudette Ballard

Gary and Connie Sims

Gary and Sue Harding

Gloria and Thomas Pearson

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Richard and Glen Plaisted

Rober and Arlene M. Pielemeier

Roy and DeAnna Berg

Sally A. Panic

Wm. D. and Joann Myers

Morey Weisman

Daniel and Nanette Douglass

Dorothy Schechter

Victor E. Kaplan

Carl Zetley

Lee and Harold Weinstein

In Honor of

The Klein's 40th Anniversary

Marilyn Cooper

Nancy Lash's 60th Birthday

Joy Tanzman

Danny Shiluma's Retirement

Emmy and Dennis Nozawa

Edith Lurie's 90th Birthday

Barbara Rothenberg

Bruce and Jeri Bartfeld

Gary Hamel

Irene Kaye

Joan Kris

John and Judy Munter

Livia Grunfeld

Louis and Bernadine Starr

Elen and Gary Silverman's Anniversary

Phil and Lauren Abramowitz

Zambler's 35th Anniversary

Joy Tanzman

Bruce Berman

Ann and Isidore Goldfarb

Pam Bolin

Robert and Patricia Jacobsen

David Jones

Todd Hulce

Richard and Irene Ilgen

Bernard Kraft

Bruce Berman

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Ethel Naray

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The Poindexter Family

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For Sale:

2002 Dodge Caravan
 IMS Conversion, Under 2000 miles!
 Call Pat Harding to Negotiate Price
 626-447-4079 or
 e-mail jackandpat@att.net

CART's Corner

Low Tech Stocking Stuffers for PALS

By Barb Phillips, MS OTR/L and Molly Doyle, MA CCC

The holidays are approaching fast!! For this holiday season, the staff at CART has several ideas for low cost items that may be purchased for PALS to help with communication and managing around the home.

Resources at the end of this article have many simple functional solutions. Check websites or catalogs for a full product line. Also, be sure to check with Ferne Hayes, Director of ALSA Equipment Loan Pool (626) 449-0605 and Linda Madole, Director of the AAC and EADL Loan programs (310) 874-3934 for any equipment that might be available to borrow.

Communication and Writing

As writing becomes more challenging, foam or rubber grips for pens can be purchased. The grip slides over the pen, making it easier to hold on to. A marker may be easier to use than a pen or pencil. Special or 'ergonomic' pens are more popular, but note that they may be heavier to hold.

Spiral notebooks are ideal for PALS who communicate through writing. Several may be purchased and placed around the house for easy access. Smaller notebooks are useful to fit in a purse or pocket.

Similarly, dry erase boards are ideal for some. The board is wiped clean after each message without needing to turn pages or worry about paper. These products are all available at most stationary stores.

In the Home

In the home, some simple items can make a world of difference. If stabilizing items such as note pads or dinner plates is becoming more difficult, non-skid rubber matting is a very handy item. It is found in stores that carry shelf-liner paper and similar products. A roll can be purchased for under \$10 and can go a long way. In the resource catalogs, a more durable version of this item is called Dycem.

If holding onto a pen, eating utensils, a toothbrush or razor is getting difficult, take some of that rubber matting, roll it around the handle and fasten with a couple of rubber bands. You can make it as thick or thin as it needs to be. Foam handles are also in the resource catalogs.

A Touch Dimmer Disc (a small plastic or brass disc) will turn any lamp into a touch lamp. The disc is placed in an easy to reach location and you never have to struggle with a switch again. This amazing item is under \$10 and available at Home Depot.

For the PALS who are finding it more difficult to stand from the sofa or bed, Furniture Risers can be purchased from linen and bedding stores. A firm cushion or pillow on the seat will also make it easier to get up.

Personal Care

For those hard to reach places, consider a long handled bath sponge or brush. Many PALS feel safer in the shower while sitting on a shower chair. If you think you would benefit from one, try the ALS Equipment Loan Pool first.

There are many different devices to help maintain independence such as buttonhooks, zipper pulls, electric toothbrushes and dental flossers. Consider elastic shoelaces or shoes with Velcro closures. Long handled shoehorns and sock aids will help with shoes and socks without having to bend over. A cup holder can position a cup nearby and a long straw will make it easier to stay hydrated.

Leisure

Holding books becomes more challenging if your arms are getting weaker. A nice book holder is available for about \$20 and has a lot of adjustments for small to large books. Robert's Book Holder is available from Maxi-AIDS.

When a table would be nice, try the lightweight Posture-Rite Lap Desk. This product is sits on your lap and can be used to rest a book, remote control, communication system or a meal.

As you can see, there are many low-tech gadgets out there to make life easier. Put in your wish lists now!

Resources

Functional Solutions (800) 235-7054 www.beabletodo.com	Maxi-AIDS (800) 522-6294 www.MaxiAids.com	MOMS (800) 232-7443 www.MOMSUP.com
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Barbara Phillips, occupational therapist and Molly Doyle, speech pathologist are two of the therapists at CART who regularly work with PALS.

ALSA Events: Walk to D'Feet ALS

Congratulations to Our Top 5 Fundraising Teams

1. Dave's Defeeters
2. Dare with Denise
3. The Third annual Jeff Weinstein Team
4. Tharnstrom/McCain Team
5. Cruisin' with Danny



Congratulations to the Top Individual Fund Raisers

1. Denise Glass
2. Marian Rozzen
3. Denise McCain-Tharnstrom
4. Gabe Devorris
5. Kathleen Rasmussen



Teams with Top Walker Registration

1. Dave's Defeeters with 122 walkers
2. Kim's Walk and Rollers – 101 walkers
The Third Annual Jeff Weinstein Team – 101 walkers
3. Cruisin' with Danny – 86 walkers
4. Carl's Crusaders – 33 walkers
5. Headway's Halos – 32 walkers



Thank You Walk to D'Feet Volunteers!

Thank you to our 200 volunteers who donated over 1500 hours for the Walk to D'Feet



Thank You to All Our 2003 Walk to D'Feet ALS Teams

A.n.n's Virtual Participants walking in honor of all PALS
Andy's Navy walking in memory of Andy Meyer
Ann's Angels walking in honor of Ann Spring
Antoinette's Hummingbirds walking in memory of Antoinette McGilbert
Armida's walking in memory of Armida Hammond
Aunt Bee walking in honor of Karen Steiner
Balozian's Team in honor of Colleen Balozian
Bertha's Angels walking in memory of Bertha Quezada
Buddy's Bridge walking in honor of Ruth Walk
Calabasas Crusaders walking in honor of all PALS
Caren's Team walking in memory of Caren Royce
Carl's Crusaders walking in memory of Carl Froya
CART's Hearts in honor Peter Weintraub
Circle K Team METRO walking in honor of Soraya Cruisin' with Danny walking in honor of Danny Shikuma
Dan's Disciples walking in memory of Daniel S. Mark
Dancers for Dorothy walking in memory of Dorothy Montoya
Dare With Denise walking in honor of Denise Glass
Dave's Defeaters walking in honor of David Rozzen
Don's D'Faeters walking in honor of Don Mitchler
Econn Family Team walking in memory of Richard Econn
Edmond's Angels walking in honor of Edmond Asouline
Ernie's Force walking in memory of Ernie Wallengren
Esqueda Soto Team walking in memory of Maria Esqueda
Ethel's Team walking in memory of Ethel Wilson
Foothill Friends walking in memory of Todd Patterson
Fortune's Faithful walking in honor of Hosea Fortune
Friends "for Life" walking in honor of Donald Piccolo
Friends of DOJO walking in memory of David Jones
Gibson Dunn & Crutcher LLP walking in honor of Michael Robyn and in memory of John Scott
Giovanna D'Angelo walking in honor of all PALS
God is Able walking in honor of Bill Roose
Grandpa Don's Team walking in honor of Don Canfield
Hard D'feeters walking in honor of Gary Hard
Hayward's Hero's walking in memory of Donna Hayward
Headway's Halos walking in memory of Betty Porrello
Henderson's Heroes walking in honor of all PALS
Hilda's Friends walking in memory of Hilda Lipman
Home Respiratory Care walking in honor of all PALS
Hummingbirds walking in memory of Jerry Schurr
Irene Weenie's walking in memory of Irene Siorida
It's Not Easy Being Green walking in memory of Harry Green
Jackie's Team walking in honor of all PALS
Jeannie's Gems walking in memory of Jeannie Hickok
Ken's Gang walking in memory of Ken Constable
Ken's Krew walking in honor of Ken Moe
Kim's Walk and Rollers walking in honor of Kim Devorris
Leo walking in honor of Sandy Krauss
Lockton Leaders walking in memory of William Morrison
Margie Oman walking in honor of Margie Oman
Marlene's Team walking in honor of Marlene Hall
Marquez Mania walking in honor of Juan Marquez, Sr.
Mary's Miracle Walkers walking in honor of Mary Hodge
McMurphy 2003 walking in memory of Brian Murphy
Mike Courtright's Angels walking in memory of Mike Courtright

Nick's Army walking in honor of Nick Berkey
Nivlac 5 walking in memory of Calvin Magness
Norma's Brats walking in honor of Norma Perez-Ramirez
Norma's Nurses walking in honor of Norma Ramirez
Olivia's Faith walking in honor of Olivia Jauregui
Patty's Shepherds walking in honor of Pat Hayes
Pedro Loza & Martha Mowatt walking in honor of all PALS
Perry & Pals walking in honor of Perry Dean
Pete's Pals walking in memory of Peter Pierce, Sr.
Rad Plaid Connelly Chicks! And Fish! walking in honor of all PALS
Rasmussen's Running for Research walking in memory of Carl Rasmussen
Rita Rodriguez walking in memory of Elle Rodriguez
Robert Golshan walking in memory of Flora Golshan
Rockey's Red Hat Flashes walking in honor of all PALS
Roger's Rebels walking in honor of Roger Milbourn
Ruby's Raiders walking in memory of Ruby Flood
Sandy walking in memory of Sandy Lurie
Sauls Angels walking in memory of Saul Tanzman
Sharon's Feet walking in honor of Sharon Loeffler
Sticker Planet's Bunch for Bernie walking in memory of Bernie Kraft
Suzanne's Supporters walking in memory of Suzanne Koehring
Tata's Team walking in memory of Hager Ismail
Team Carter walking in memory of Todd Carter
Team Enzer walking in memory of Melvin Enzer
Team GoGo walking in memory of Alice Pregenzer
Team Linda walking in honor of Linda Bauersachs
Team Sandler walking in honor of Murray Sandler
Team Shannon David Walking in honor of all PALS
Tharnstrom/McCain Team walking in memory of Robert McCain
The 2nd Annual "A" Team walking in memory of Agnes Ameer
The Third Annual Jeff Weinstein Team walking in honor of Jeff Weinstein
Valentina Caruso walking in memory of Valentina Caruso
Walk till you drop walking in memory of Esther Ramirez
Walk with Cathy and Liz walking in honor of all PALS
Walkin' with Falk-Balser in memory of Gertrude Falk
We Care walking in honor of all PALS
Weezie's Team walking in honor of all PALS



Simple Wishes

"Simple Wishes" Creates a Delightful Friendship

By Melea Balwan

I'd like to share the story of a "simple wish" that brought 3 strangers together to form a special friendship. I met Mike Robyn around October of 2002 when I volunteered for "Simple Wishes," with ALSA.



Mike and his wife Abby welcomed me into their home with open arms. Initially, I went to Mike's home to assist him with completing a report for a work project that had been left unfinished. I was to dictate his words and write them down.

Now, I need to explain that Mike uses an alphabet board with his eyes to express all his basic needs, novel ideas, etc... So, I initially needed to become familiar with Mike's communication style. Mike was very patient and encouraged me to learn "rapidly!!!" I picked up pretty fast! There would be days that we would only write 2-3 sentences because Mike would easily fatigue. This was an exhausting process for him; however, he would always push himself to the "last straw" before stating he was too tired. I admire Mike for his dedication and will-power.

As Mike and I became closer and started visiting on a personal level, Mike began to ask a lot of personal questions about my work, family, etc... Without hesitation we would spend hours talking about interesting topics, his family, or social events. Every time I left Mike's house I would look back on our visit together and marvel on the amazing strength Mike displayed. Could he really be so devoted and interested in somebody else that it would improve his overall quality of life? His wife reported so and it was apparent!

One day I explained a relationship that I have with a private patient of mine. Mike was fascinated to learn more about little, Jesus Morales. Every visit Mike would ask about Jesus. Wow!!! With all that Mike deals with day-in and day-out, he is more interested in a 10-year-old boy's life, his therapy, schooling, and medical appointments than his own. Mike and Jesus first met via a phone conversation. It was a wonderful experience. I was with Jesus at his home and we called Mike and Abby. Jesus conversed with Mike, asked him questions, and responded to Mike's interesting questions. Before long, Mike began sending letters and gifts to Jesus. The Robyn and Morales families started to interact via letters, phone conversations, and finally we made a visit.

The first visit to the Robyn home was very emotional for all. Jesus' parents and I arrived at the Robyn's with awareness of Mike's very involved medical condition. Upon arrival, just as any 10 year old would do, Jesus became shy and scared to talk. This is where Mike's strengths kicked in! Mike initiated conversation as I interpreted his words from the communication board into English and Spanish. Jesus' speech is moderately dysarthric using a speaking valve to allow him to speak. The Robyn family demonstrated good understanding of Jesus' speech, encouraging him to talk more. Later, Jesus told me that he was so scared to see Mike. He stated that he never thought Mike would understand his weak speech. I encouraged him to continue talking to strangers and other familiar people because many people do take time to listen, especially "special people" like Mike. Jesus and Mike have both encouraged each other to keep fighting and never give up. They have a very special relationship.

Now, Jesus and Mike have frequent phone conversations and are pen pals. In all we've visited twice and are planning a carousel adventure in November. I can't explain how enlightening this experience has been. Jesus, Mike, and I share common bonds that have improved our quality of lives. For some, the quality of sharing, giving, and loving is forgotten. For Mike and Jesus, these qualities enlighten them and give them that quality of life they deserve! For me, this is why I LOVE my profession and am encouraged to keep fighting for all my patient's, family, and friends! There is nothing more special than enlightening a human spirit!

Thank you ALSA for my "Simple Wish."

Melea Balwan is a Speech Pathologist in CART at Rancho Los Amigos National Rehabilitation Center.

ALS Gene Study

Researchers at the Massachusetts General Hospital are seeking individuals with ALS and their family members for participation in the ALS Gene Study, conducted by Dr. Robert H. Brown, Jr. This NIH-funded study focuses on finding the causes of ALS through an examination of both the genetics and environmental risk factors. The ALS Gene Study is an ongoing research study in collaboration with Northwestern University.

Blood samples from individuals with ALS and their parents and/or siblings are currently being accepted for this research project. Participants will be asked to complete questionnaires about their environment and family history, and for permission to review medical records pertaining to the onset and progression of the disease. The Massachusetts General Hospital will cover all costs for participation; travel to Boston is not necessary to participate in this study. The researchers are happy to help to make arrangements for the blood samples to be drawn locally.

Lastly, although there are no direct benefits for those involved in this research, the research team at the Massachusetts General Hospital believes that understanding the causes of ALS will lead to more effective screening, diagnosis, treatments, and a cure.

To help find a cure, please contact:

Alayna Barnes-Nessa, Phone: (617) 726-5750 e-mail: abarnesnessa@partners.org

S. Mark Taper Patient Services

How We Help
Ann Ver Planck, MA
Director, Patient Services

The Patient Services Staff of our chapter provides many different services to PALS each month. We want to share some examples in each newsletter so you can get an idea of how we might help you. Even if you think we can't possibly help, I hope you'll call on your case manager, or the Augmentative Alternative Communication and Equipment Loan Pool Directors for assistance with any problems you have. We might be able to assist even if you think your problem is impossible to solve.

- A PALS was covered under her husband's COBRA insurance, but it looked like coverage would be terminated and the family were worried that she would not be eligible for disability benefits or Medicare, as she does not have enough working quarters to qualify for Social Security. The chapter case manager referred them to A.C.C.E.S.S., (The Advocating for Chronic Conditions, Entitlements, and Social Services Program) and the State Dept. of Health Insurance Assistance Program to obtain more information about the state's high-risk medical insurance pools. Her husband made some phone calls and was relieved to learn that his wife could qualify for other medical plans after her COBRA coverage ends.
- One PALS required in-home X ray services as she is ventilator dependent and it's difficult for her to leave home. Because she's prone to developing pneumonia she needs frequent X rays. Our case manager was able to find such a service and now the PALS and her family don't need to take an ambulance to obtain this necessary service.
- One PALS has small children and very low income. Her medical plan does not provide medical equipment coverage or the disposable medical supplies required for her care. Our Equipment Loan Pool was able to loan her everything she needs to allow her to continue living in her home and care for her children.
- Over a holiday weekend, a PALS caregiver did not show up and no one in the family was available to care for her. The family called the ALSA case manager who worked to find a facility that was willing to help. After numerous phone calls he located a nursing home director who arranged a bed for a few weeks until the family could make other arrangements.
- Our Augmentative Communications Director was able to intervene with a PALS' physician who refused to make a referral for a speech evaluation. After speaking with the doctor several times, the director was able to help him see that a speech evaluation was a "basic need" for an ALS patient and that to not help with that need could prove detrimental to the PALS' health and well being. The physician finally agreed and the evaluation was obtained. Unfortunately, the insurance company did not cover the specific communication device that was prescribed, however, the device was available through the chapter loan pool and we were able to deliver the perfect device to her at no cost.

My Mother's Caregiving Story by Janet Lowry

It was once said that "a story is the passageway to authentic living." Stories have a way of comforting us, challenging us, teaching and reminding us of the important lessons in life in a way that facts or ongoing lists simply cannot. Stories are like invitations into others' experiences, without which we would be left to walk through our lives in solitude.

Recently, I asked my mother to tell me her story. She is the primary caregiver to my uncle, her brother, who has been living with ALS for over three years. She fills numerous other roles as well including those of wife, mother, daughter, sister, professor, mentor, counselor and friend. Clearly, my mother has a number of stories she could tell. However, what she wanted to share most was the story of how she continually helps our family understand, grieve, question, share, grow, and ultimately embrace the experience of life with ALS.

First and foremost, my mother shared the importance of settling the details and moving beyond them. She talked of lawyer visits, final wishes, estate planning and so on, all to simply say those are legitimate, practical concerns. However, these concerns must be acknowledged, dealt with, and then put aside. Life beyond the tasks must be reached.

Next, my mother talked of the importance of a safe place. A safe space must be created where everyone including PALS, friends, family members, and caregivers are invited to share their honest reactions. Feelings must be welcomed, encouraged, and acknowledged regardless of how deep, how new, or even how relevant they are. Emotions must be treated as unique and priceless and not addressed with clichés, generalizations, or expectations. The results of such an environment will be trusting relationships, authentic communication, and deepened understanding.

Finally, my mother's story concluded with the importance of focus. Living life, rather than losing life, should be the focus for everyone. In addition, the PALS and family should be encouraged to see each day as a gift for everyone, not just for the patient. Again, life is truly lived when the focus is taken away from tasks and obligations and instead put on opportunities, service, and emotional growth.

It's funny how stories work. Someone talks about their experience and we all connect somehow. Either we see ourselves in their place now, recognize that place as a part of our past, or anticipate our arrival someday soon. But, wherever we are now, we are blessed to share the journey.

Janet is a student at Pepperdine University



ALSA Events: Walk to D'Feet ALS

Thank to Our 2004 Walk to D'Feet ALS Volunteers!

**200 Strong, from More Than 22 Organizations,
 Donating Over 1500 Hours of Service**

Serving from:

Agoura High School
 ALS Association Board of Trustees
 ALS Association National Office
 American Humanics
 Bel Air Presbyterian Church
 Cal Lutheran University
 Chaminade High School
 Circle K International – Metro
 Community Health Charities
 Crespi High School
 Gardena Buddhist Church
 LKM
 Moorpark College
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 – Conejo Valley
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