

SIGN UP NOW FOR OUR GOLF TOURNAMENT 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. 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.



2003 Walk to D'Feet ALS
Saturday, October 4, 2003
Reed Park, Santa Monica
California Avenue & 7th Street

Registration begins at 8:30 a.m. and the walk will begin at 9:30 a.m. For more information, please call Giovanna D'Angelo, Director of Special Events (818) 865-8067. Please visit our web site at www.alsala.org



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

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SAVE THE DATE!

UPCOMING EVENTS



June 19, 2003
Lou Gehrig's 100th Birthday! See July 5th for celebration information!

June 27, 2003
"Dance for Life" Dance Recital! R&B Dance Company will be hosting a charity dance recital to benefit The ALS Association in Torrance! Please join us! See inside for more details!

July 5, 2003
Lou Gehrig's 100th Birthday Celebration at Dodger Stadium! Come join us for a fun day at the Dodger game and PALS-related pre-game festivities! See inside for more details!

July 21, 2003
Authentic Swing Charity Golf Tournament and Inaugural Game Day & Boutique, 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

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Volume 2, 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

June 19, 2003
Lou Gehrig's 100th Birthday!

June 27, 2003
"Dance for Life" Dance Recital! R&B Dance Company will be hosting a charity dance recital in Torrance!

July 5, 2003
Lou Gehrig's 100th Birthday Celebration at Dodger Stadium! Come join us for a fun day at the Dodger game and PALS-related pre-game festivities!

July 21, 2003
4th Annual "Authentic Swing" Charity Golf Tournament and Inaugural Game Day & Boutique, North Ranch Country Club, 9:00 a.m.

October 10, 2003
"Walk to D'Feet ALS Walk" Reed Park, Santa Monica. Preparations are beginning now to make this year's walk better than ever!

NEWS!

Visit our web site at

www.alsala.org

MESSENGER

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

Tuesdays with Morrie - A Primer on Life for June Graduates

By Molly Rockey

Once a teacher, always a teacher. And so, PALS Morrie Schwartz, just couldn't help himself from teaching when he began to have weekly visits from his former student, Mitch Albom. Those visits turned into Morrie's personal "lessons I have learned in life" lecture series. The world has been blessed that Mitch saw the value of those lessons learned at his teacher's bedside and created the book Tuesdays with Morrie.



Students in Mrs. Barb Kellogg's senior English class at Agoura Hills High School hold their copies of Tuesdays with Morrie and pose for a graduation photo.

Now, five years after his death, Morrie Schwartz is still at work, teaching students all over the world through Mitch's small book. The book teaches us to open our hearts, to give back to our communities, to be kind to ourselves and to be compassionate and loving. The book was the inspiration for a class project at Agoura High School where English teachers Mrs. Kellogg and (Continued on Page 9!)

Lou Gehrig's 100th Birthday Celebration Set for July 5 at Dodger Stadium

The ALS Association is proud to announce the details of one of the most exciting event of the year. On July 5, 2003, The ALS Association and the Los Angeles Dodgers baseball club present "ALS Association Day at Dodger Stadium" celebrating Lou Gehrig's 100th Birthday with our 2002 Walk to D'Feet Team Captains, family members, caregivers and major donors.



The festivities will focus on increasing awareness of ALS and will include a variety of events, on and off of the field. The festivities will begin at

(Continued on Page 9!)

Sign Up Now to Become a Team Captain for the 2003 Walk to D'Feet ALS!

Plans are underway for our biggest fundraising event of the year! Reserve the date of October 4th for the Walk to D'Feet ALS at Reed Park in Santa Monica. Last year over 1,000 strollers and rollers paraded down Ocean Boulevard, up San Vicente and back to Reed Park, enjoying cool ocean breezes along the way.

This year's event will be held at Reed Park again and promises to be bigger and better than ever! Last year our fundraising success was boosted by the number of people who followed a few simple steps. To find these steps, turn to page 8 in this newsletter! We look forward to seeing you there on the 4th!



ALSA Greater Los Angeles Chapter News

News from Board President John Krave

It is always wonderfully heartening to see awards and recognition conferred upon persons who seek no reward other than the satisfaction that comes from selfless devotion in the service of others. We had such a rewarding experience in May at the ALSA National Leadership Dinner when our own dedicated staff and volunteers won an array of awards that signify their dedication and commitment to PALS and the mission of the Greater Los Angeles Chapter.

Most notably, the Chapter won honors for Excellence in Leadership Development. Thanks to the leadership of Molly Rockey, our Director of Volunteer Services, our Chapter increased its volunteer corps from 27 to over 575 between 1999 and 2002, an increase of over 2000%. By promoting volunteer opportunities at The ALS Association through many campus-based recruiting events at Pepperdine University, the word spread and some excellent volunteer leaders of tomorrow joined the fight against ALS. These volunteers worked with the Chapter to recruit more and more of their peers to join the fight, as well as arranging for Molly to speak to over 800 students about The ALS Association's Greater Los Angeles Chapter and the lifelong gift of volunteering.

ALSA-GLAC also took home the Patient Services, Support Services Achievement Award in Monolingual Case Management. The Chapter received this honor for reaching out to and providing services to Spanish speaking members of the ALS community. The Chapter also won the Poster Award for Community Service by a Chapter for its presentation titled, "Community Outreach to PALS by Connecting with Local Neurologists." The poster was created by Pepperdine MBA student team members Yekaterina Yevmenkina, Steve Ziemniak, Scott Herz, Jennifer Jacobsen and June Satimanont. We thank them all.

These honors offer strong evidence of the Greater Los Angeles Chapter's commitment to and focus on maximizing patient service and outreach. With your help, we can continue our vital mission.



Pepperdine University award winning team: Jennifer Jacobsen, Yekaterina Yevmenkina, June Satimanont and Steve Ziemniak.



Ismail Tsieprati Wins 2003 March of Faces "Ultimate Awareness" Award

Congratulations to Ismail Tsieprati for winning the 2003 ALS March of Faces "Ultimate Awareness" Award. Ismail, a film producer from Simi Valley, was nominated for the award by ALSA case manager, Jackie Neff, and won the award with the help of his wife, Cheryl. Ismail co-wrote, directed and produced two educational videos for PALS and their family members, "Caring for the Caregiver" and "It's Your Choice." These videos are available through the Chapter's video loan pool. Contact Joan San Fillippo at the Chapter office or your case manager to receive a loaner copy. Thank you, Ismail and Cheryl for donating your \$500 prize to our Equipment Loan Pool Fund!



Ismail Tsieprati, shown with his wife, Cheryl, was recognized by ALS March of Faces for achievements on behalf of those with Lou Gehrig's disease

Dr. Linda Sepulveda Awarded 2003 "Angel of Hope" Award

Sometimes there are people in our lives who are like bright shining lights. They are the ones who lead us through our darkest days, lift our spirits with their words of hope and encouragement, enlighten us with their wisdom, hold our hands and touch our hearts. One of those special people is Linda Sepulveda. The Greater Los Angeles Chapter of The ALS Association honors Linda with our first "Angel of Hope" award, presented by Molly Rockey at the May 17th Ask the Experts. We thank Linda for her devotion and dedication to the ALS community and for the guidance she has given The ALS Association.



Dr. Linda Sepulveda is presented with the first "Angel of Hope" award at the May 17th "Ask the Experts" event in recognition of her tireless efforts on behalf of The ALS Association and our PALS

- Dora Escamilla**
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- Tom Giambra**
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- Carmen Verdugo**
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Employees Community Fund Boeing of California
for "Ask the Experts" Educational Programs

Gladys Daily Coffman Trust for Patient Services,
Ventura County

Lon V. Smith Foundation for Volunteer Services
PDI (Aventis Pharmaceuticals) for Ask The Experts
The Ayrshire Foundation for the Equipment Loan Pool

The Geliebter Foundation for
2003 Authentic Swing Golf Tournament

To see if your company matches your charitable contribution,
please check out web site!

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The ALS Association of Greater Los Angeles Chapter
P.O. Box 565, Agoura Hills, CA 91376-0565
phone: (818) 865-8067 / fax: (818) 865-8066
email: ALSAGLAC@aol.com

web: www.alsala.org



ALS ASSOCIATION
Greater Los Angeles Chapter

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 February 26, 2003 to May 31, 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.

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.

Spring Appeal \$500+

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Sid and Don Greenberg
Colleen Hulce
Jan and Edward Woods
Caryl Golden and Bob Zinner

Spring Appeal

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S. Mark Taper Patient Services



Making the Most of Your Doctor Visits

by Janet Yamanishi, Case Manager

Doctor appointments are something dreaded by most of us, sometimes viewed as a waste of time and occasionally we

feel we leave with not much more information than we had when we arrived. Here are some things to keep in mind before your next appointment.

- When scheduling your appointment keep in mind the best time of day for you. Does it take you awhile to get up and going in the morning or are you slowed down by the afternoon?
- If you are going to need assistance getting to your appointment, call ahead to your transportation source to confirm the time. Allow ample time so you aren't rushed and don't arrive at your appointment feeling hurried.
- When you get to the doctor's office, will you need assistance getting settled into the examination room or perhaps need a larger room to accommodate your wheelchair? Make this known to the staff when you call to schedule your appointment.
- Have your questions ready for the doctor: write down your questions at home before your appointment and don't let your doctor leave the examination room until you are satisfied that you have had each question answered. Doctor appointments are scheduled pretty close together and once the doctor has left the room, it is next to impossible to have the doctor return.

With pre-planning you will be able to conserve your energy, have your questions answered and leave your appointment with a sense that going to your appointment was worth your time and effort.

Chapter Wish List

- 1000+ ANSI Lumens LCD/DLP Projector for Chapter Presentations, Support Groups and Events
- 25" Color TV / VCR / DVD Combination for office, training and event use
- Heavy-duty 4-drawer filing cabinet
- Laptop for presentations (>14" LCD screen, >1 Ghz Processor)
- 16-Port 100/100 Base-T Ethernet Switch/Router
- Volunteers with BIG trucks to move electric wheelchairs and beds

If you can help out with these needs, please contact Molly at the Chapter office at (818) 865-8067 or via email at molly@alsala.org



Today's Riddle

by Joyce Lauterback, PT, MFT, Support Group Leader

What has 20 to 48 eyes, sluggish and careful movement, capable of emitting electronic sound and has a heart as big as a coliseum?

AN ALS SUPPORT GROUP!

Our support groups have anywhere from 10 to 24 people in attendance each month. Some people walk in and some people have wheelchairs and roll in. Some folks have their own voices and some come equipped with speech devices to help them communicate.

The support group is designed for both PALS and their family and friends to learn more about the day-to-day questions, concerns, problems and solutions of living with ALS. Sometimes we have family or friends attend without the PALS. One of the reasons for this is that a loved one afflicted with ALS does not live in Southern California. The family member still wants to understand ALS and learn useful information so they can assist and be supportive long distance.

Another, more common than not, reason is for the family member of the PALS to act as a "Scout." Often, people who are diagnosed with ALS, especially those very recently diagnosed, are afraid to attend the groups. I have heard this fear repeated many times over during my four years as a support group facilitator. New PALS are afraid to see the limitations of other PALS. They are afraid to look at what their future might be. So they send family members to attend meetings for a couple of months. Following the reassurances of the "Scout", PALS will then venture into this scary realm known as the ALS Support Group.

They will see people in wheelchairs, using walkers and needing assistance for transferring in and out of the car. They will hear the automated speech of augmentative speech devices or the whispers of PALS who use a lot of energy to express themselves. But...they will NOT see limitations! New PALS and FALS will experience an indomitable spirit and free reigning humor used to manage this beast called ALS. They will be enveloped by the enormous heart of the group and the care and compassion freely exchanged amongst our members

That is because every individual within the group knows exactly what you are going through. Every member of the group has gone through it, too.

S. Mark Taper Patient Services



Conductora del Grupo de Apoyo

by Martha Mowatt, Case Manager

El grupo de apoyo en español siguió floreciendo apesar de que ha cambiado bastante en el último año. Cambiamos nuestro lugar de reunión hasta que encontramos uno que nos a dado mejor resultado. Hora nos reunimos en la biblioteca de la ciudad de South Gate. Anteriormente, nos reuníamos cada tercer sabado del mes. Ahora nos estmos reuniendo cada tres meses (enero, abril, julio, octubre), en el tercer sabado. Todos estan invitados a participar en el grupo. Durante nuestras reuniones, hacemos amistades con otras personas viviendo con ALS, aprendemos como sobrevivir los retos de la enfermedad y haveces nos desahogamos. Si les interesa volver a reunirnos cada mes, solamente hagamelo saber. Tiene algun tema que le interese que presentemos? Por favor comuniquese con migo y hare todo lo posible por complaserlos. Los esperamos en la ciudad de South Gate!

Para preguntas e información, comuniquese con Martha Mowatt, (562) 889-9452.

“Living with ALS” Manuals Now On-Line!

The ALS Association is delighted to offer a series of six “Living With ALS” manuals on the National office’s web site at www.alsa.org. First provided in 1997, the set of manuals fast became the most valuable single informational resource for the ALS community.

The manuals have been updated and are designed to be read in the order that is most helpful and meaningful to the person with ALS and their family – based on the individual’s symptoms. The manuals include:

- | | |
|-----------|---|
| Manual #1 | What’s It All About |
| Manual #2 | Coping With Change |
| Manual #3 | Managing Your Symptoms and Treatment |
| Manual #4 | Functioning When Your Mobility Is Affected |
| Manual #5 | Adjusting to Swallowing and Speaking Difficulties |
| Manual #6 | Adapting to Breathing Problems |

Naturally, the reader may have questions about their own situation after reading one or more of the manuals. We encourage you to discuss the information in the manuals with your healthcare provider and ALSA case manager.

SPECIAL NOTE: Living with ALS – Part 3, by Denise Glass will appear in our next edition, due in September of 2003.

Tips for the Newly Diagnosed

by Tom R.

Just wanted to share some practical matters with any newly diagnosed PALS. This is just a list of ideas, some I did, some I didn’t and some I wished I had.

- The very first thing to come to grips with is that ALS is bigger than any one person or family. You will need help. There are agencies and organizations out there to help you. Find them and take advantage of what they may offer. This is not the time to prove to anyone that you can do it alone.
- There is a tremendous amount of information on the Internet. I encourage you to find it and use it.
- Get your finances in order. You can protect assets from this disease, but you must do it now.
- You will be advised to go to specialists. You will want the best medical care. Follow the guidelines of your insurance plan! Ask before you act. Do not be afraid to ask the specialist what the charges will be and if they will accept what insurance will pay.
- When the time comes, use a cane, walker, or wheelchair to conserve energy and protect your body. The last thing you need is a broken bone or bruises.
- Be careful with far out treatments that claim to cure. The soundest advice I got, was that if the claims were true they would be front-page news.
- I suggest installing grab bars early, especially in the bathroom.
- Wireless keyboards are wonderful for those who have the ability to type. We had the house wired for a computer network and could then literally use a computer to type out anything on the television, as I lost my voice. This was a great help.

SUPPORT GROUP SCHEDULE

Westside Group:

American Red Cross Building
VA Grounds, Room 7
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, CA 91361
Fourth Saturday of the month,
1 p.m.
Contact: Joyce Lauterback
(818) 421-9729 for topic/speakers

Pasadena:

Lamanda Park Library
140 South Altadena Drive,
Pasadena, CA 91107
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. Se reune
cada tres meses.

ALSA Events: Summer Event Update

Golf Tournament at North Ranch Just Around the Corner!

The ALS Association is proud to announce the 3rd Annual “Authentic Swing” Charity Golf Tournament at North Ranch Country Club on Monday, July 21, 2003. The day starts with a continental breakfast, open driving range and putting green. A celebrity auction will kick-off the tournament as celebrity “5th Members” will be offered to the highest bidder! Current celebrities scheduled to play include Pat Boone (music), Mark Gubicza (baseball), Raefer Johnson (Olympian), Tommy Lee (musician), and Wes Parker (baseball). More to be announced on the web site!

The tournament will consist of a best-ball scramble format with various hole competitions throughout the round at the beautiful North Ranch Country Club including closest-to-the-pin, longest drive, \$5 birdie hole (with corresponding margarita station!), hole-in-one contest, “beat the pro”, and putting contest at the turn. The tournament will conclude after 18 challenging holes with cocktails and hors d’oeuvres while eyeing a collection of silent auction items on the patio. For those who qualified for the putting contest finals, the final shootout will occur just before the dinner reception.

The dinner reception will begin at 5:00 p.m. in the banquet room at North Ranch Country Club. Prizes will be awarded to winning golf participants and various sponsors, volunteers, donors, and friends will be recognized for their efforts towards this event and the organization. The evening will conclude with the closing of the silent auction items and an exciting live auction, with some amazing prizes to be sold to the highest bidder! This year’s tournament promises to be better than ever! Last year, over 120 golfers participated and helped raise over \$70,000 for local ALS patient services. This year, we have set \$80,000 as our fundraising goal. Tickets are \$300. Contact the office for more information or to register!

Gehrig 100th Birthday Details!

(Continued from Page 1)

11:30 a.m. with an on-field player “meet-and-greet” for top-fundraising PALS and caregivers. On-field ceremonies will conclude just before game time with an ALSA-sponsored ceremonial first pitch by PALS Gary Hard.

In addition, the Dodgers are planning to air ALSA-related public service announcements to help raise awareness of ALS within the community.

Off the field, The ALS Association will be issuing Lou Gehrig baseball cards at all turnstiles and will be sponsoring the “World’s Largest Jersey” signing outside of the stadium to further drive awareness among the baseball community. We are looking forward to a great event at Dodger Stadium and will bring you a full recap in the next issue!

Game Day Tournament Features Mah Jongg, Bridge, and Bunko at North Ranch!

The ALS Association is proud to announce the Inaugural Game Day and Boutique at North Ranch Country Club on Monday, July 21, 2003. This event will occur simultaneously with our 3rd Annual “Authentic Swing” Charity Golf Tournament, also located at North Ranch. Click here for more information on that event!

Please join us for a fun-filled day of Mah Jongg, duplicate or party bridge, bunko, a delicious buffet lunch, raffle and a wonderful boutique at the prestigious North Ranch Country Club ballroom! The entry fee is \$50 (\$30 tax deductible). Gather your friends and come play as a team! Mah Jongg players will need to bring their own playing sets in addition to their 2002-2003 National Mah Jongg card!

The game day will conclude at 4:00 p.m. with a small awards ceremony, raffle and last round of shopping at the boutique. All participants are invited to join the golf tournament participants in cocktails and hors d’oeuvres while eyeing a collection of silent auction items on the patio for an additional \$75 (including dinner banquet). Contact the office today for more information or to register!

Tuesdays with Morrie - A Primer on Life For June Grads

(Continued from Page 1)

Mr. Partain, with the help of Morrie Schwartz, lovingly navigated their classes of seniors through the most important lessons of life before launching them into the adult world. When I learned that Chapter office assistant, Nicole Haley, was one of those lucky students, I grabbed the opportunity to visit her classroom and share a video of Morrie Schwartz’s 1998 “Nighline” interview with Ted Koppel. Nicole’s class had just finished reading Tuesdays with Morrie, but did not have a face to put with the man of wise words. Before playing the videotape, I shared with the students the work of The ALS Association and how ALS strikes not only 78-year olds like Morrie, but people as young as 23. We talked about all the different kinds of “graduations” that each of us goes through during our lives, including the final one, on the last day of our life. As the students watched the film, there was a hush over the room, then giggles, moans, gasps and tears. Over a two-day period, 150 seniors began to see Tuesdays with Morrie as more than a homework assignment, but rather a manual they can refer to throughout life. As Nicole Haley shared with me, “This book changed my perspective on life. It pointed out what’s really important and what really matters.” We decided together that even though we cannot visit with Morrie on Tuesdays anymore, we can spend two minutes with Morrie anytime by simply reading a paragraph or a page or two from Tuesdays with Morrie.

Steps to Take Now to Ensure Your Team's Success in the 2003 Walk to D'Feet ALS!

Last year our fundraising success was boosted by the number of people who followed these three simple steps:



- 1) Form a team or walk as an individual. A walk team is two or more people – family, friends, co-workers, church members or service clubs – who want to join in the fun and raise money to support The ALS Association. It's easy to start a team – just choose a team captain and a team name and register your team on www.alsala.org.
- 2) Set your own personal goals and team goals and start raising money! Ask everyone you know to support your participation. Collect donations as you talk to people. Last year our success was boosted by the great number of families who participated in our national letter writing campaign*. We encourage everyone to begin gathering a mailing list of friends, family and neighbors who will team up to raise funds for research to find a cure and to support the work of our Patient Services Department. Mail a personal letter to everyone on your list asking them to join your walking team on October 4th, gather donations from their friends and neighbors and make a personal donation. We have found that you will double your success if you include a self-addressed, stamped envelope along with your letter.
- 3) Watch for your walker's registration form in the mail in early August and check the Chapter's web site at www.alsala.org for up-to-the-minute information.
- 4) Save the date of our kick-off event on July 31st in Santa Monica. Details on this event will follow.

*This year, students from Pepperdine University will be in our office on Saturday, September 6th to assist PALS with their letter campaigns by helping to compose letters, photocopying, addressing and stamping envelopes and even dropping them off at the post office. All we need is a copy of your mailing list and your letter or your idea for a letter. PALS, if you would like to have students provide this free service for you, please contact Molly Rockey at the Chapter office at 818-865-8067 or molly@alsala.org.



Is a Talking Communication Device for Me?

By Carlene MacBride, MA, CCC-SP

In previous articles, CART (Center for Applied Rehabilitation Technology) has discussed various techniques to assist PALS with communication depending on their current needs. Previous articles focused on strategies to maintain use of speech, and the use of writing and other "low technology" options, such as alphabet or communication boards to augment or replace speech.

For some PALS though, the above methods may not work or may not be enough. With these individuals a high-tech communication system may be considered. It is highly recommended that the PALS receive a formal evaluation to determine which high-tech communication device will be appropriate for them. One thing that must be considered is the progressive nature of ALS. Motor control and needs change with time. Some "high-tech" devices have flexibility built in, others do not.

What is a high-tech communication device?

A high-tech communication system is generally something that is electronic and has voice output; that means that the device will "talk." Some communication devices are dedicated strictly to communication, while other systems are actual computers with added communication software. These computers can still be used for word processing, internet and other computer related tasks. All high-tech communication systems have pros and cons. The important thing to remember is that it is the individual's needs and skills that dictate which device is optimal for any particular person.

How do I make the device talk?

You can type out and then "speak" your message or program and save common phrases for use at a later time. These phrases are individualized and specific to your wants or needs.

Some PALS may be able to type information into the device, similar to using a keyboard on your computer. For others, using hands or fingers to type a message may be difficult. Therefore, adaptive equipment may be recommended to use with the device.

Still for other PALS, use of hands or fingers to type a message may be out of the question. A completely different method of typing will need to be considered. For those individuals a switch may be used to input and retrieve messages. The PALS only requires a consistent movement in one place on their body in order to use a switch. The movement does not need to be big or take a lot of effort, but it does have to be consistent and one that can be done repeatedly without fatigue. This movement can be anywhere! It can be a toe, an elbow, a head turn, a flicker of a finger or in some cases, an eye blink. Once the location of switch placement is determined by the professional doing the evaluation (usually an occupational therapist), the PALS can type out messages into the communication device.

How much is a communication device and how can I afford one?

Communication devices with voice output can range in cost from approximately \$1,000 to \$9,000. It is very important that a PALS be appropriately evaluated for one of these devices as they are extremely costly and you will want to be appropriately "fitted." A speech pathologist, in conjunction with an occupational therapist, usually conducts the evaluation. At times, a physical therapist or technology specialist is required to address positioning or equipment mounting issues.

Fortunately Medicare, Medi-Cal and various insurance programs will fund these devices. In order to get funding, a speech pathology evaluation and written report is required. The evaluation is specific to the equipment the PALS requires based on their communication needs and abilities. This report is reviewed by the funding agency that will approve or deny the equipment.

The ALS Association has an AAC equipment loan program that may be able to assist you. Contact Linda Madole at 310-874-3934 or lmadole@charter.net. The Muscular Dystrophy Association (MDA) is available for funding assistance. Contact Morris Lawson, ALS Coordinator for MDA at 310-450-3103.

Carlene MacBride is a Speech Language Pathologist at the Center for Applied Rehabilitation Technology, CART at Rancho Los Amigos National Rehabilitation Center. The phone number for CART is (562) 401-6800 and the web site is www.rancho.org/cart.

2003 CAREGIVER SUPPORT GROUPS

San Gabriel Valley

San Gabriel Unified School District, Conference Room
408 Junipero Serra
San Gabriel, CA 91776
Meets: Thursday, October 2, 2003 - 11:30 am to 1 pm

Westlake Village, Ventura County

City of Westlake Village Library/City Hall, Community Room
31200 Oak Crest Drive
Westlake Village, CA
Meets: Wednesday, November 5, 2003 - Noon to 1:30 pm

Long Beach

American Red Cross, Long Beach Branch, Room 1
3150 E. 29th Street
Long Beach, CA 90806
Meets: Thursday, August 7, 2003 - 11:30 am to 1 pm

Westside

American Red Cross, Located on the VA grounds
11355 Ohio Avenue, Room 7
Los Angeles, CA 90025
Meets: Thursday, September 4, 2003 - 11:30 am to 1 pm

NOTE: Sessions are open to ALL caretakers. Contact: Dillon Woods at (310) 358-6043 for more information about any of the above caregiver support groups



A Review of Our 2003 Advocacy Efforts

By Dr. Jeannie Fontana, Advocacy Chair

This year's Advocacy Day on Capitol Hill was once again a powerful experience.

Nearly 600 people participated from around the nation, with a VERY impressive turnout from PALS themselves. Representing our Greater Los Angeles Chapter were Molly Rockey, Peter Pierce, John Krave, Dean Rasmussen (who flew in from Paris), Linda and Oscar Sepulveda, Denise Noyer, Jenny Keppler, Ward Digby and myself. Together our team met with representatives or their aids to share ideas and information about ALS.

This year we had an EXTREMELY powerful tool, a short documentary featuring four of our PALS, Andy Vaughan, Ernie Wallengren, Jeff Weinstein and Denise Glass, personally asking for support for ALS issues. The film allowed the viewer to witness the rapid physical changes a person with ALS experiences as it switched back and forth between early photos of PALS and the videotape. Everyone who saw the film was moved and everyone said they wanted to help. Our goal on May 1st was to gain support on four main issues:

- 1) Continue the increase in federal funding for research at the National Institutes of Health (NIH) by 15.8 percent (\$3.7 billion)
- 2) Request the Department of Defense allocate federal funds for research to better understand about how environmental factors may be involved in ALS;
- 3) Pass legislation to make ALS a presumptive diagnosis, receiving Social Security Disability Benefits when the PALS decides to stop working;
- 4) Support the Lifespan Respite Care Act of 2002 authorizing federal grants to the states that would jump start the creation and enhancement of respite care programs across the country.

While we feel confident about the inclusion of ALS in the Department of Defense Budget and that PALS will receive Social Security Disability Benefits, the harder road may lay in the NIH funding at its current 15% and the Respite Care Act. If you want to help and are interested in receiving training on becoming a local ALSA Advocate, please contact Molly Rockey at the Chapter office at (818) 865-8067 or e-mail Molly@alsala.org.

Top (left to right): Peter Pierce, Linda and Oscar Sepulveda and Molly Rockey prepare for their next appointment.

Second (left to right): Senator Barbara Boxer (center) meets with the Greater Los Angeles Advocacy

Third (left to right): 2003 Advocacy Team: Greg Stuart, Denise Noyer, Ward Digby, Jenny Keppler, Jeannie Fontana, Dean Rasmussen, Molly Rockey, Peter Pierce and John Krave. (Linda and Oscar Sepulveda not pictured).

Right (left to right): Ward Digby, Molly Rockey, Peter Pierce, Congresswoman Hilda Solis, Jeannie Fontana, Jenny Keppler and Denise Noyer.



2003 March and May "Ask the Experts" Programs

By Molly Rockey, Education Program Coordinator

The H.P. and Sophia Taubman Educational Symposia Series presented two dynamic programs this spring.

Palliative Care and End of Life Issues in ALS

On March 15th, healthcare workers from all over Southern California gathered in Santa Monica for "Palliative Care and End of Life Issues in ALS." The program was designed for nurses and those professionals working in the fields of hospice and palliative care. Presenters from the UCLA MDA/ALS Clinic and Research center included Dr. Michael Graves, Medical Director; Dr. Linda Sepulveda, Clinic Manager; and Dr. Judith Ford, Director - Palliative Care Unit. Also presenting were Dr. Cecile Falk-Balser, ALSA Board of Trustees member; and Darcy Bulthuis from Trinity Care Hospice. Respiratory issues and decisions that are routinely faced by staff treating ALS patients were discussed by a panel of therapists from Home Respiratory Care including Diana Guth, Glenn Noble and Brad Erickson. Lora Clawson came to the conference from Johns Hopkins University, School of Medicine, to share the work of the Robert Wood Johnson Foundation on end-of-life issues.

This program was videotaped and will be available through our video library.



Top: Speakers (from left to right): *Standing:* Glenn Noble, Darcy Bulthuis, Dr. Judith Ford, Dr. Michael Graves, Brad Erickson. *Seated:* Lora Clawson, Dr. Linda Sepulveda, Diana Guth, and Dr. Cecile Falk-Balser

Above: Members of the ALS Association (from left to right): Jeff Henderson, Molly Rockey, PALS Denise Glass, Joan San Filippo, Giovanna D'Angelo and Jeff Dix at the "Fearless Living with ALS" Program



Top: Lori Butler and Van Ballew present "26 Miles of Friends - My Marathon Experience"

Above: Volunteers from American Express and Pepperdine University join staff in welcoming everyone!

Fearless Living with ALS - II

When PALS and family members were asked last year "what kind of educational program would be most helpful for you?" the respondents overwhelmingly asked for presentations for PALS and caregivers given by PALS and caregivers. They wanted answers to questions like "How do you get through the day?", "What do you do to keep your spirits up?", "When do you get out of the house and where do you go when you do venture out?" Great questions that need thoughtful answers. We set out to invite PALS who were recommended by case managers and friends to share what they have learned about living with ALS in southern California. Everyone who was asked to present responded with an enthusiastic "YES". The day proved to be an inspirational one for PALS, family members, staff, Board members, volunteers, vendors and even the employees of the Doubletree Hotel in Santa Monica. By the end of the day, there were smiles all around and we each felt like we had been given a breath of fresh air, a moment to laugh together and some great tips for facing the challenges of living with ALS with a brave heart. Thank you to our presenters: Carl and Barbara Frova, Dick Levitt, Pat Hayes and Doreen Thompson, Kari Kramer for the Moe Family, Van Ballew, Martha Mowatt for Jose Medrano and our own favorite clown, Denise Glass!

This program was videotaped and will be available through our video library once edited.