ALS ASSOCIATION®

MESSENGER

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SAVE THE DATE!

The H.P. and Sophia Taubman Foundation Educational Symposia Series presents:

Developing a Subspecialty in ALS: An Educational Program for Healthcare Professionals

Saturday, January 26, 2002
8:30 a.m. to 3:00 p.m.
Holiday Inn Los Angeles City Center, 1020 South Figueroa Street, LA

INSIDE THIS ISSUE

DON'T MISS THIS

Your Mother Should Know a daughters journey with her mother and ALS.

Through December 15th, Friday's and Saturday's 8:00 pm, at The Two Roads Theatre, 4348 Tujunga Ave., Studio City, $12. For reservations call: 323-650-7305

JEFF'S SPECIAL TEAM

BY EVA WOLPE—Shortly after the diagnosis of ALS became clear in my mind, without the real understanding of the meaning or even knowing the correct spelling of the disease, the first thought that came in my mind was, why us? Why Jeffrey?

Then I went to my first ALS Association support group meeting. When I looked around the room and I watched the faces of patients and caregivers, I felt an emotional attachment and closeness. Through their anguish I realized that rather than question "why Jeff?", the question I should ask was, "how can this suffering be ended?" And I knew from that moment on. I became a Diamond Walk team member and it felt so very good. So on that early Saturday morning, stepping out of the van and seeing a bunch of turquoise and red T-shirts buzzing around Exposition Park, my feet were ready for walking!

For a bystander this gathering most likely looked like a family picnic; people hugging and kissing. But if they looked a little bit closer they would have noticed that the hugs embraced a little bit tighter and the kisses were not just the conventional peck on the cheeks. We were connected through our love, our concern, our need for each other and eagerness to face our common enemy.

The morning was overcast although we were basking in a golden glow which usually comes from the sun. The sidewalk rendered an invitation for a walk, we responded by lining up and we started walking! As I looked around, the hard work and determination of the volunteers was evident.

Our relatively small group, so enthusiastic and eager, seemed to be swelling to the size of any major walkathon. The Los Angeles Chapter of The ALS Association managed to close down the route to all traffic. If someone thinks it doesn't make you feel strong and powerful to walk down the middle of Figueroa, ignoring all the traffic

Continued on page 3

CASE MANAGEMENT SERVICES

BY ANN VER PLANCK, MA, PATIENT SERVICES DIRECTOR—The Chapter offers Case Management services to PALS and their families who live in our Chapter service area. I'm happy to announce that we have recently hired a Case Manager for Ventura County. Even though you may never have accessed these services a case manager has been assigned to you.

Case management service areas in LA County are divided roughly by the 60 Freeway. If you live below the 60 Freeway, your case manager is Janet Yamanishi (310 316 1626). If you live above the 60 Freeway, your case manager is Lothar Delgado (626 799 2218). And, if you live in Ventura County, your case manager is Jackie Neff (805 526 7234). If you still aren't sure who your case manager is in LA County, please contact Ferne Hayes, 626 449 0605 who willbe happy to refer you to the correct person for your area.

Case management services for our Spanish-speaking PALS and their families are provided by Pedro Loza. Please contact him at 562 928 5048.

Los servicios del Manejador de Casos para personas con ALS de habla Hispana y sus familias son proporcionados por Pedro Loza. Avísele por favor al 562 928-5408."

IMPORTANCE OF NUTRITION

BY PEDRO LOZA, CASE MANAGER—To many of us, getting a meal is as simple as going to the market or nearest fast food restaurant. Reality is, many people have limited means to receive one or two meals a day. I'm neither speaking about the homeless nor the abandoned. Look no further than our own ALS community. I recently sat with a family who was in this situation. I did what any other human being would do. I started searching for community resources and found a few very willing to assist. Having a daily meal is very important to everyone especially to those who suffer from this disease. "Until more effective drugs are developed and approved to treat ALS, measures to improve patients' mobility and quality of life remain the mainstay", explains Jeffrey Rothstein, M.D., PhD., associate professor of neurology at Johns Hopkins University School of Medicine in Baltimore. "Nutrition is very important. A recent study in Italy showed increased survival in ALS patients who received good nutrition." That is why it is very essential for ALS patients to maintain a healthy daily diet. There are many programs like Catholic Charities and Salvation Army providing meals to low-income families. Catholic Charities has been involved with ALS families by providing them with meals when needed. If you find yourself in a situation where you are unable to provide for yourself or family, please contact Ferne Hayes (P.S. Liaison) who will direct you to one of the Case Managers.

DE PEDRO LOZA, MANEJADOR DE CASOS—A muchos de nosotros, obtener una comida es tan sencillo como ir al mercado o restaurante. La realidad es, hay muchas personas limitadas a medios para recibir una o dos comidas diarias. No estoy hablando acerca de personas sin hogar o abandonados. No mire tan lejos porque en nuestra propia comunidad de ALS existe esto. Yo me senté recientemente con una familia que estaba en esta situación. Hice lo que cualquier otro humano haría. Comencé buscando recursos entre la comunidad y encontré unos pocos muy dispuestos a ayudar. Una comida diaria es muy importante para todos especialmente a los que sufren de esta enfermedad. "Hasta que las drogas más efectivas se desarrollen y sean aprobadas para tratar ALS, las medidas para mejorar la movilidad de pacientes y calidad de la vida permanecen neutral, dijo Jeffrey Rothstein, M.D., PhD. "Nutrición es muy importante. Un estudio reciente en Italia mostr" sobrevivencia aumentada en pacientes de ALS que recibieron buena nutrición." Es por eso qué es muy esencial que pacientes de ALS mantengan una dieta diaria saludable. Hay muchos programas como Caridades Católicas y la Salvación de Ejército que ayudan a familias de bajos ingresos. Las Caridades Católicas se han implicado con familias de ALS proporcionándolos con comidas cuando sea necesario. Si usted se encuentra en una situación dónde están ustedes incapaz de proporcionar para usted mismo o para la familia, por favor de contactar a Ferne Hayes (Enlace de Pacientes) que se lo dirigirá a uno de los Manejadores de Caso.

FIVE WISHES

BY LOTHAR DELGADO, MA—I came across a document recently that, in the light of all that has changed since September 11th, seemed fair to me. It is called "Five Wishes". It is a living will that talks about your personal, emotional and spiritual needs as well as your medical wishes. It is a way of saying exactly how you wish to be treated if you become seriously ill. No one will have to guess what you want. Your loved ones will not have to make the difficult choices without knowing what your wishes are. Rather, they can be beside you to support you. If you change your mind you can change the document. It is for anyone over the age of 18—married or single, parents, adult children and friends. Over one million Americans have already used it and it can be ordered by simply calling 1-888-5WISHES (1-888-594-7437)

Here are the Five Wishes:

My Wish For:

- The Person I Want to Make Care Decisions for Me When I Can't
- The Kind of Medical Treatment I Want or Don't Want
- How Comfortable I Want to Be
- How I Want People to Treat Me
- What I Want My Loved Ones to Know

There are many things in life that are out of our hands, but the way we are treated at the end of our life does not have to be one of them.

WE WELCOME OUR NEWEST CASE MANAGER

BY JACKIE NEFF, MSW—For the past ten years, I have worked for St. John's Regional Medical Center's Acute Rehabilitation Unit as their Clinical Social Worker. In my work with hundreds of patients young and old who were struggling with new disabling illnesses and injuries, I am acutely aware of their need and their families to have health care professionals assist them during the rehab and recovery process—not only in the rehab team providing therapy services to improve the patients' functional levels—but also for our staff to provide supportive counseling to patients/families to assist them with major disability adjustment issues and lifestyle changes. This interdisciplinary approach to treatment helped to facilitate better recoveries and lives for our patients/families.

Over the coming weeks and months ahead, I look forward to meeting everyone and am eager to start working with the Ventura County PALS and their families.

HOW TO COPE WITH FEARS AS YOU EXPERIENCE YOUR BODY DETERIORATING DAY AFTER DAY?

BY JOHN JONES, MFT—There are as many different ways of coping as there are individuals, and the methods of coping can vary from day to day, and sometimes, even minute to minute. I remember one person saying: "Having ALS is a bitch!" "Getting up in the morning, trying to tie your shoe laces to go to work, why? what for?" This person decided to go on disability, and enjoy life: It was mentioned that following the support group meeting, they were looking forward to having a gin martini and then were planning to do some traveling." Other persons in this same support group mentioned that seeing their grandchildren was the best. A third person in this same support group stated that they are taking a college course, which they've always wanted to do. A family member thought that having their parent hear some talking books in the "homeland language" might be soothing. Others pray. This is just a sample that came out of one support group meeting.

It is so easy for us to think or assume we know what's best for the person with ALS, that we might forget to ASK THEM. I imagine that having been diagnosed with ALS propels a person into another realm, one that we don't truly understand, because we don't actually experience it. This different "realm", for lack of a better term, can involve very different methods of coping.

My suggestion is that you just might be coping the best way that you can given both your history and this diagnosis. What do you think?

I welcome your reactions, thoughts and feelings at our next support group.

HAPPY HOLIDAYS FROM THE PRESIDENT

BY CECILE FALK BALSER—This has been a year of hard work and successful endeavors for our Chapter. As documented in this issue, we have continued to have outstanding events with many friends coming together to make them possible. We at The Greater Los Angeles Chapter want to thank you for your participation and your generosity. In addition, we want to wish you and your families a happy, healthy and successful New Year. We look forward to working with you in the coming year with a sense of hope and optimism for all who have been touched by ALS. Thank you and happy holidays.

WANTED!

By the Volunteer Services Department

Small, portable VCR player for training purposes
If you have one to donate please call
Molly Rockey at the Chapter office –
818-865-8067

Jeffs Team, from page 1

signals, I challenge them to come and walk with us next year.

The streets are almost deserted because it is relatively early for a Saturday morning. But as the walkers push ahead they bring energy, and life, and laughter, and hope, and determination. The oily gray cement under their feet resonates with “ Yes we can! Yes we can!” The bright turquoise and red T-shirts turn Figueroa and Adams and Jefferson into a blooming “field of dreams”.

This is my first “walk” and it is for ALS Association’s LA Chapter. Among the walkers is my son-in-law, Jeff, who was stricken with this disease about two years ago. At about the same time, he was blessed with an over abundance of positive attitude which seems to overflow and help all of us. We have the family, and we have the friends, and the friend’s friends, and his children’s friends and over twenty members of his future daughter–in-law’s family!

The goal is to finish the walk through the colorful balloon arch into the arms of fellow walkers and have that million dollar feeling with every step you take. Along the route there are well-wishers and volunteers offering cold bottled waters and smiles and cheers for the remainder of the walk.

We sometimes slow down or speed up to greet a friend, to steel a hug, crack a short silly joke and just go on walking because quitting was never an option.

The first group of walkers was just reaching Vermont heading toward Exposition and on to the finish line and we are not far behind. Actually I can see the arch and I reach over and grab the hand of Bobsha (Gina’s grandma).

The two of us positioned ourselves at a very distinguished location. We crossed the finish line with Jeff! I am Jeff’s mother-in-law, Eva. I am 73 years old and Bobsha is 80 years old!

HOW ACCESSIBLE IS YOUR HOME?

Steps to remaining Independent in your home (First in a series)

BY ADAM FINE, PRESIDENT, ACCESSIBLE DESIGN AND CONSULTING, INC.—Thinking about making your home, office, or apartment accessible?

Please ask yourself the following questions if you are considering an “accessible modification”:

Exterior Steps

- Are the steps in good repair? (are they smooth and/or safe surfaces to walk/roll on?)
- Are the stair treads deep enough for your whole foot?
- Are there any hazardous open risers on your stairs?
- Do the steps have a non-slip surface on them?
- Are there handrails on both sides of your stairway?
- Is there enough grasping space for your knuckles and fingers in between the railing and the wall?
- Is your threshold leading to the doorway ½” or less?
- Is there a shelf beside your front door to rest your packages?

Interior Stairways

- Can you safely go from one level to another level in your house?
- Are the steps in good repair? (are they smooth and/or safe surfaces to walk/roll on?)
- Are the stair treads deep enough for your whole foot?
- Are there any hazardous open risers on the stairs?
- Do the steps have a non-slip surface on them?
- Are there handrails on both sides of your stairway?
- Is there enough grasping space for your knuckles and fingers in between the railing and the wall?

Obviously, one cannot cover all of the possibilities in such a brief article such as this but completing the above check-list should be able to give you some very good ideas about some of the things to consider should you wish to make your home more accessible. For more information visit our website at ***www.AccessibleConstruction.co****m or check with your ALSA case manager.*

COMMUNICATION BOARDS: A LOW-TECH ALTERNATIVE

BY CARLENE MACBRIDE, MS, CCC—Communication boards can be useful tools if you are no longer able to depend on speech and/or writing to effectively communicate. Communication boards can be custom made to best fit your needs and physical abilities. The best type of communication board can be determined through an evaluation with your speech/language pathologist and occupational therapist.

Various boards can be created to meet your needs and abilities. If you need to spell out messages, an alphabet board can be created. The lay out of the letters can be customized and organized so that it is comfortable for you. For example, some individuals prefer that the layout resemble a computer keyboard, where others prefer the layout in standard alphabetical order.

Some individuals prefer that frequently used words and phrases be placed on the board along with the alphabet. This allows you to select both words/phrases as well as letters to increase your speed of communication. Examples of words/phrases that may be on a communication board can include frequently requested wants and needs, or names of family members who are frequently talked about.

At times, it may be difficult to place all words, phrases and letters on one board because of a limited ability to point to these items. For some individuals, having several boards can be very useful. Boards can be created with vocabulary and phrases specific to an activity, or specific to a topic. For example, one PALS who likes to play cards on a weekly basis with friends, may require a board that contains the alphabet and key phrases that relate to the card game. Boards can then be swapped depending on the communication interaction.

Boards are not only customized for content, but also how they will be accessed. If you have limited movement and it is difficult to reach all the letters and words on a large board, a smaller board may be created so that little movement is required to select each target.

If you are having difficulty pointing with your finger, partner assisted scanning or eye gaze may be used to help you access what you want to say. Partner assisted scanning involves the listener pointing to each row of letters or words/phrases written on the board. The PALS then indicates when the listener reaches the desired target in that row by showing a positive response. This response could be a head nod, a lift of a finger, closing of the eye, etc. Once the row is determined, the listener begins to scan and point to the items in that row until he receives a positive response from the PALS that the target letter, word or phrase has been selected.

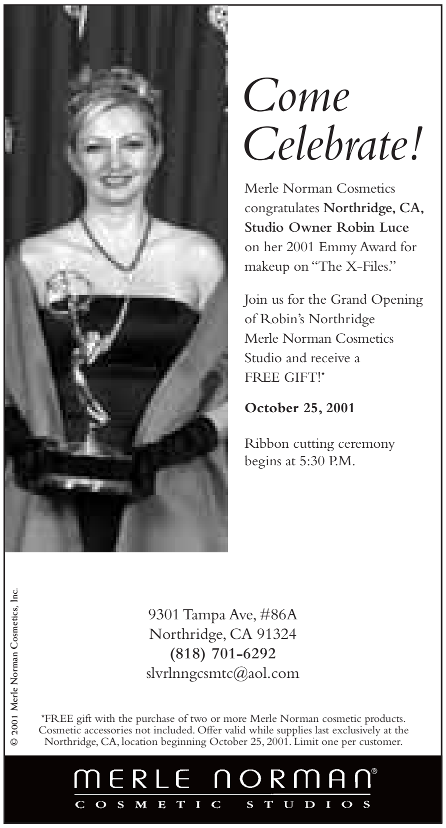
Eye gaze is another approach that may be used when pointing with your finger is physically too difficult. Boards can be specifically set up to allow the PALS to look towards the letter or words he desires to communicate. Letters and words can be spaced on a board to make it easier for the listener to interpret where the PALS is looking to communicate. For some individuals, placing the words and phrases into four quadrants is preferred because it is easier for the listener to read the PALS eye movements. Once the quadrant is determined, partner assisted scanning can be used to determine the specific item within the quadrant.

The design and layout of a communication board will be influenced by your needs, who you communicate with, and how you physically access your messages. A communication board that works well for one person, may not be the optimal layout for another person. The best communication board for you can be determined through an appropriate communication evaluation.

For examples of communication boards, the following resources are available:

Linda Madole (Director of Augmentative Communications for The Greater Los Angeles Chapter of The ALS Association) (310) 514-8228

Carlene MacBride Yonemori, MA, CCC, is a speech/language pathologist at the Las Floristas Center for Applied Rehabilitation Technology (CART) at the Rancho Los Amigos National Rehabilitation Center. If you have questions regarding this article, please contact CART at (562) 401-6800.



INFOLINE

BY MARTHA MOWATT, MONOLINGUAL SUPPORT GROUP LEADER— Have you ever had a question or a problem and did not know where to begin? Have you ever stared at a phone book wondering who would best answer your question? A great resource to have on hand is Infoline. Infoline is a resource and information service available 7 days a week. Whatever your question, their trained staff are able to direct you with your inquiry. Whether you are looking for food banks, legal assistance, employment or job training, domestic violence information, housing, senior services, immigration, family planning, or what ever you may be in need of, they are sure to have a phone number for you. Infoline offers bilingual services. So the next time you are in need of a resource, don't delay in getting help. Call Infoline, they will be happy to assist you.

Infoline 800-339-6993

Alguna ves ha tenido una pregunta o algun problema sin saber a donde acudir? Ha mirado al libro teléfonico sin saber quien le puede ayudar a resolver su problema? Un recurso que debe de tener a la mano es el numero de teléfono de Infoline. Infoline es una linea telefonica de asistencia de informaci"n y recursos que esta disponible los siete dias de la semana. Cualquier sea su pregunta o problema, Infoline le tendra un numero de teléfono a donde llamar. No importa que este buscando, le pueden ayudar con su pregunta. Si esta buscando recursos de comida, asistencia legal, entrenación de trabajo, servicios dómesticos, asilo, servicios para adultos de tercera edad, imigración o planificación familiar, Infoline le puede ayudar. La proxima ves que necesite ayuda, no sequede sin asistencia, llame a Infoline. Infoline ofrece servicios bilingues.

Infoline 800-339-6993

SIMPLE WISHES FOR THE HOLIDAYS

Attention PALS!

Want a Simple Wishes volunteer to help you with your Holiday cards and phone calls?

Please contact Molly Rockey, Director of Volunteer Services at 818-865-8067 or alsaglac@aol.com

ALSA — LA CHAPTER SUPPORT GROUPS

Westside

American Red Cross Building, VA Grounds, 11355 Ohio Avenue, Los Angeles, CA 90025, Meeting Room 7; First Saturday of the Month

For Information, Contact Support Group Leader John Jones, MFCC (626) 524-7081

Monolingual (Spanish) Support Group

Note: New Location
Clifton M. Brakensiek-Bellflower Public Library/Biblioteca Publica Clifton M. Brakensief, 9945 E. Flower Street, Bellflower (On Flower St. between Bellflower Blvd. and Woodruff Ave.); Third Saturday of each month from 3:00–4:30 p.m.

Contact: Martha Mowatt at (562) 889-9452 for more information.

Pasadena Support Group

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

Contact John Jones, MFCC at (626) 524-7081, for more information.

Ventura Support Group

City of Westlake Village Community Room, located at Westlake Village City Hall and Library, 4373 Park Terrace Drive, Westlake Village, Fourth Saturday of each month, 1:00–2:30 p.m.

Contact: Joyce Lauterback (818) 421-9729 for more information

EFFECTIVE COMMUNICATION

BY JOYCE LAUTERBACK, MFT—In most relationships, healthy communication is an important element of staying connected to those we care about. Sometimes we get in our own way because we make assumptions about what a person's response or reaction will be when we tell them what we are thinking or feeling. We fear a negative response. With ALS, there may be a tendency to avoid honest communication because of guilt or protection or denial. Rather than bringing people closer, this avoidance usually creates more distance. When one is struggling with the everyday losses of ALS, increased emotional distance is the last thing a person needs.

The way we communicate (or not) can be habits we acquired or behavior we learned from our family or culture. Here is a five step plan to change these old patterns.

Sensory Data: Be aware of what you are observing, using your senses. What do you see in another's facial expression, gestures, movement, posture? What do you hear in his/her tone of voice, volume or words? Is there physical touch or none? What are the physical sensations you are experiencing?

Be aware of your thoughts. We have beliefs that can limit or expand what we experience. Often, based on beliefs or past experiences or expectations, we create our own interpretation of the sensory data we are observing. It is not always an accurate interpretation.

Notice what you are feeling. When we have an encounter with someone, our emotions seem to occur instantaneously. However, our feelings are usually based on the interpretation we just made. Paying attention to your feelings can inform you about new or unresolved issues.

Know what you want for yourself and for the other person. What you want for yourself shows caring about yourself. It is what you want from the other person. Your wants for the other person is a genuine acknowledgement and understanding of what they want for themselves.

The action you choose is the result of how you have processed information in all the previous steps. In this category are past actions – the way we have always responded, present actions – what we will do currently, and future actions – these reflect ways we might want to change.

Here is an example:

The issue is Joe, the husband and caregiver really wants to take Marie, his wife and PALS to Oregon to visit his sister. A trip she has always enjoyed. Marie does not want to go. Joe's healthy communication with Marie might go like this: "Marie, when we talk about this trip, I notice that you (sensory data) change the subject or give a reason we cannot go on a specific date. You will wheel out of the room and avoid me. Your voice becomes abrupt and drops a couple of octaves. Your face changes from smiling to a stern look. I think (thoughts, interpretations) that you don't trust me to manage your needs or the wheelchair or that you don't like my sister any more or that you don't want to travel with me. (feelings) I'm upset about this and I feel guilty because I know you are not as strong as you were the last time we went. (wants for self) I really want for us to go to Oregon in the next month. My sister and I aren't getting any younger. Winter will soon be here and I don't want to drive in bad weather. (wants for other) I also want you to take the opportunity while you are still physically able, to enjoy the relaxing atmosphere at my sister's and to enjoy the road trip like you always have. (past action) You know, I have always just kept quiet and don't say anything when we have a disagreement about something like this. I just shrug it off and don't bring it up again because I don't want you to be mad at me. (present action) But this time, I want to have a conversation about it. I want to know what you are thinking and feeling. (future action) The next time there is a disagreement, I want us to be able to deal with it when it is occurring without your feeling mad or me feeling guilty."

Other points to consider in effective communication are the ability to listen to the other person without interrupting him/her and reflecting back to them what it is you heard so that they know you understand their perspective. This also allows for clarifying any item that may have been misinterpreted.

For example, Marie's response: "It sounds as though you think I don't trust you. Joe, of course I trust you. You take wonderful care of me."

It is also important to use "I" statements rather than you statements. "I feel really upset" rather than "You make me crazy." "I" indicates that the speaker takes responsibility for his/her feelings and thoughts. "You" tends to make a person feel blamed and accused and usually results in a defensive reaction.

This approach to effective communication takes time and effort at first because you are changing ingrained patterns. Once you practice using a new approach, it then becomes very natural. The best reward, however, is a renewed closeness with those we care about.

EARLY AAC INTERVENTION

BY LINDA MADOLE, MA-SLP—This month, I would like to discuss the importance of early AAC (Augmentative Alternative Communication) intervention, for PALS whose ability to communicate has been affected. I have encountered PALS who are in the late stages of the disease, whom never sought help for their communication deficits until recently. The loss of communication can rightfully leave one feeling isolated, hopeless and afraid. Getting help early on can bring hope and solace, as well as a better quality of life!

Some people may have come to associate AAC with some sort of communication device only. The thought of using one may seem daunting to some, as well as cumbersome, or overwhelming. This is not the only means of alternative communication, however. And, in many instances this is not the most appropriate solution, either! There are actually three categories of AAC solutions available to assist people with ALS. Many people use a variety of solutions to fit individual lifestyles and varying communicative contexts. These categories are as follows:

No technology: Twenty questions, facial expressions, gestures, eye-pointing, partner assisted scanning. These types of strategies can be used by PALS with any degree of communication deficit. It may be beneficial to begin utilizing these types of strategies as soon as a communication decline is noticed, so that the PALS and caregivers/significant others can develop strategies that work best for everyone. Some people may develop a code, such as three blinks would mean "No", and one long blink would mean, "Yes". The idea is to determine what works best for the PALS and their listener(s). Speech pathologists are trained to help with this process, if necessary.

Low Technology: Some form of chart or alphabet board, and some means to access it; or handwriting (e.g. pen or pencil & paper, dry-erase boards, magic slates) Writing is such a natural form of communication for most people, that PALS with adequate hand movement will usually adopt this strategy with ease (as writing can be used to convey anything from a short phrase to a lengthy story). There is a myriad of different types of alphabet boards available, and these can be tailored to individual needs and preferences.

High Technology: Use of an electronic device either, dedicated or multipurpose in function. Dedicated devices are used to produce digitized or synthesized speech output for face-to face communication (e.g. Dynavox 3100, LightWriter SL-35, LINK). Multipurpose devices use specialized software, in conjunction with a computer or laptop, to accomplish all tasks one does on a computer in addition to the speech output function of a dedicated device (e.g. Words+ Freedom 2000, Polyana).

A speech pathologist can assist with determining the most appropriate AAC strategies and solutions. I am happy to assist anyone with the process of receiving an evaluation from a certified speech-language pathologist. You may feel free to contact Linda Madole, Director of Augmentative Communication, at (310) 514-8228, or via e-mail: lindamadole@home.com.

MESSENGER

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.

P.O. Box 565
Agoura Hills, Ca. 91376-0565
(818) 865-8067
fax (818) 865-8066

WEBSITES OF INTEREST

ALS-KIDS "What is ALS?" for KIDS—
www.march-of-faces.org/KIDS/moe7.html
ALS-Kids- A Virtual Journey—
msnhomepages.talkcity.com/SupportSt/foxyrayj
Medicines for low income families—**www.themedicineprogram.com**

PALS Linda Rosas meets LA Laker Rick Fox at the Laker training gym in El Segundo

NOT SO... SIMPLE WISH

BY BOBBI JEAN TANBERG—Linda has had ALS for about nine years. A dear friend, and part time care provider, sent in an application to the Simple Wishes program in March of 2001. Her Simple Wish was to meet LA Lakers player Rick Fox.

After months of failed phone calls, and a realization that this Wish was no so "simple", I was able to make a connection through the Laker organization with the Dream Foundation. They would help me! Arrangements were made for four tickets to a Laker game for Linda and her two children – and me. It was a special night for all of us, but especially for Linda. After years of watching her team play from a chair in her living room, she was finally able to see them in person. There is just nothing like the excitement in the air when the Lakers are playing their best – and winning! We all thought that that was the end of it, and we were all happy to have had this special night together.

It was two months later that I received a call from Julie at the Dream Foundation. She had never forgotten that Linda had made that special request to meet Rick Fox. He was going to be in town on July 6th! Could I make arrangements for Linda to be transported to the LA Lakers training facility in El Segundo? Of course!

Linda was overcome with emotion as Mr. Fox entered the conference room. He sat down and talked to her and then escorted us down a hallway of photos of the many legends of the Lakers franchise. We stopped in a large office with a window overlooking the practice gym. In front of the window was a credenza displaying the NBA Championship Trophies. Linda and Mr. Fox posed for a few photos with the trophies before he was off to the practice court. A few last minute photos in the gym and it was time for us all to say goodbye. Tears of joy and gratitude flowed.

All of us are hoping this wonderful experience will help Linda stay healthy through the season. Linda's daughter reports that she is still glowing from the experience.

They say a picture is worth a thousand words, I think the joy on Linda's face in this photo is worth a million words. I feel very blessed to have had the opportunity to get to know Linda and her family, and to see first hand how the anticipation and fulfillment of this dream has impacted each of them – even though is was a "Not So Simple Wish".

VOLUNTEER SERVICES — IT TAKES WHAT IT TAKES

BY MOLLY ROCKEY—On Saturday, October 6th, before sunrise, when the misty night air clung damply to the grass and yellow light still glowed from the street lamps, volunteers began to arrive at Exposition Park to help with the Diamond Walk – Downtown. Students from Pepperdine Univerisity's American Humanics program, USC's Phi Delta Theta Fraternity (Lou Gehrig's own fraternity), UPS volunteers from the Neighbor to Neighbor program, sisters from Kappa Kappa Gamma, Kappa Alpha Theta, Alpha Delta Pi at USC and even more Trojans from Pi Kappa Alpha showed up to work in teams. They joined volunteers from The National Charity League and Singles Helping Others, Key Club members from Marshall High School, students from Sigma Pi Alpha at UC Riverside, service leaders from Lockton Insurance, members of Grace Community Church, angels from Don Francisco's Coffee, helpers from Excel Communications and Aventis Pharmaceuticals, friends and family of our PALS, ALSA Board of Trustee members, and even PALS themselves, all coming together to help with this major fundraiser. They tackled such varied jobs as putting up a thirty foot antennae, placing over 400 street barricades along the 5K walking route to ensure traffic safety, setting up registration and water stations, posting directional signs throughout the park and at major intersections, manning face painting, ALSA Chapter and team flag booths, handing out baseball cards as souvenirs at 1st, 2nd, and 3rd bases and greeting participants with baseball "trophies" as they crossed home plate in front of the Los Angeles Coliseum. We needed you, each and every one of you! Our volunteers do so much more than simply accomplish tasks, they bring their extraordinary talents, smiles filled with optimism and an uncommon willingness to pitch in and do whatever is needed to ensure success.

Sincere thanks to each and every one of you for making all of this happen with such joy! The volunteers of the ALS Association's Greater Los Angels Chapter remind us every day by their extraordinary service why the United Nations declared 2001 the International Year of the Volunteer.

STAYING ACTIVE WITH WHEELS

BY FERNE HAYES, PT—EQUIPMENT LOAN PROGRAM DIRECTOR/PATIENT LIAISON—Many people with ALS lead active lives and continue to do so while managing the symptoms of the disease. Frequently the use of a wheelchair enables one to get around safely and also to conserve energy. Even those who have no difficulty walking safely find they can enjoy the restaurant, the theatre, the mall, or family event more if it hasn't taken over half of their effort just to get there!

Since it takes a great deal of energy and upper body strength to self propel in a manual wheelchair, most people with ALS do not make good wheelchair 'propellers'. Family and good friends quickly learn how to look out for curb cuts and other accessible pathways and how to fold a wheelchair and lift it in and out of the trunk (lock those wheels) or backseat (let the wheels roll on in).

Some folks will want to consider a power (battery operated) wheelchair or scooter. It is very liberating to be able to move around independently in a power operated vehicle. Here are some considerations:

Do you have a good place to use a power chair or scooter?

Power operated vehicles must be operated on level surfaces with adequate clearance for turning corners. Furniture may need to be rearranged inside a home or office to allow wider pathways.

If there are stairs, there must be a ramp or vertical lift. Ramps should have a minimum width of 36", edges at least 1½" high, and a length at a ratio of 10–12" length for every 1" stair height. Ramps longer than 8 feet must be adequately braced and have adequate landing space at every turn. Many thresholds also require ramping for safe use in a power wheelchair or scooter.

Out of doors a level hard surface pedestrian walkway in good condition is required. A slight forward incline of 10o or less can be managed if the surface is also in good condition. A power wheelchair or scooter should not be operated sideways on an incline in a position where the rear wheels are not on the same plane with each other or on uneven ground or on a roadway meant for automobiles.

Contact Ferne Hayes, PT, Equipment Loan Program Director/Patient Liaison at 626-449-0605 or elpferne@aol.com.

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DONATIONS, MEMBERSHIPS AND MEMORIALS

The Greater Los Angeles Chapter of the ALS Association is truly grateful for the support we receive. The following acknowledgment lists persons and groups who contributed to our organization during the period of July, 2001 through October, 2001. Through this donation and support program the Chapter provides a way to remember and pay tribute to those who struggled valiantly in battling ALS. In addition, because of your caring 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 also request a supply of tribute envelopes to have on hand at the funeral home by calling (818) 865-8067.

Individual Donations $1-$500

Frances Alvarado
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Lenny Baluyut
Irwin and Arline Borovay
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Daniel and Lori Azemar

Gil Smith's 70th Birthday
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FROM THE EXECUTIVE DIRECTOR...

Debi Klein, ED

Events in retrospect

BY DEBI KLEIN—What a whirlwind year of events this has been. Hundreds of supporters joined PALS, families, friends and volunteers to raise much needed funds for patient services and awareness of ALS. I would like to thank our sponsors who made these events truly successful:

Wine Affair 2001:

Rasmussen Foundation
Mrs. Robert (Betty) Strub
Carol Econn

Find Your Authentic Swing Golf Classic:

EPI General Contractors
R.S.V. Sport, Inc. (LEI)
Mr. and Mrs. Paul Meyer
Law Office of Gary Freedman
Lockton Insurance Brokers, Inc.
Swat-Fame, Inc.
C.A. Rasmussen
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Ball Development Corporation
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Automobile Club of Southern California
Wood Ranch BBQ & Grill
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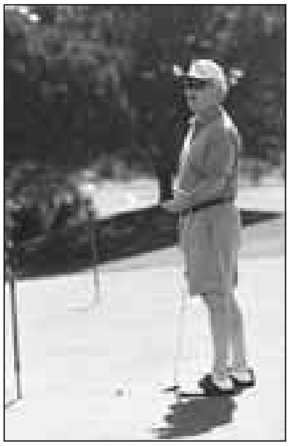

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Golf Classic Chair

Carol Econn, our "Bud" Grier
Achievement Award Honoree

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Carol Econn
Lois Ferguson
Melvin and Susan Geliebter(R.S.V. Sports, Inc./LEI)
Michael Schneickert
US Trust Company
Gregory and Donna Econn
Geri Enzer
Timi Loomis Freshman
Peggy Fritchey
Pacific Century Bank
Thelma Higgins
Barry and Cathy Pearlman
Howard and Lynn Safenowitz
John and Rosemary Schwimmer
Gary and Ellen Silverman
Alberto Valner

Diamond Walk Downtown:

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James Econn & Co. Insurance
The Emerson Glazer Foundation
Gibson, Dunn & Crutcher
Richards, Watson & Gershon
Ernest Goldenfeld
Korn Ferry International
Lockton Insurance Brokers, Inc.
Downtown LA Motors, Shammas Automotive Group
Sherwood Insurance Services
Union Bank of California
United Parcel Service
Wells Fargo Bank

I would also like to thank the committee members who guided these events from beginning to end:

Tip Your Hat to Fashion and Friends Fashion Show and Tea:

Ginger Attaway, Emily Bresler, Joyce Fortune, Ellie Runken, Lynn Safenowitz, Marilyn Way

Find Your Authentic Swing Golf Classic:

George Powlick, James Rasmussen, Tim Casey, David Davis, Bryant Kolsin, Chris Ludlow, Ellie Runken, Art Schwartz

Diamond Walk — Downtown Committee:

Elizabeth Bluestein, Dan Borchers, Ray Cardenas, Clark D'Sousa, Carol Econn, Joyce Fortune, Robert Golshan, Julie Hafner, Eloise Helwig, Nao Hirashima, Dawn Andrews McIntosh, Cathy Ostiller, Peter Pierce, Melanie Ransford, Suzanne Thompson, Megan Tunnell, Rosa Vongchanglor, Arlene Williams, Keith Wilson

Our grand finale event, The Diamond Walk-Downtown was truly awesome! Walkers energized by the festive music and inspiring words, joined one another in a sea of turquoise tee shirts, and strolled through the newly beautified Figueroa corridor. Over 200 volunteers from 18 organizations, cheered our walkers on, handing out water, baseball cards and baseballs! We walked in honor of our PALS, in memory of our loved ones and we walked for those who cannot walk. We walked for hope, we walked for a cure!

Soon we will be sending out "save the date" postcards to alert you of our 2002 event schedule. Please join us for these special times, we would love to have you.