ALS ASSOCIATION® MESSENGER

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SAVE THE DATE!

Ask The Experts 2001
for PALS, family members, care givers and health care professionals
Radisson Hotel — Westside
May 5, 2001

Golf Tournament
Northranch Country Club
July 23, 2001

Fashion Show and Afternoon Tea
Northranch Country Club
July 23, 2001

Walk-A-Thon
Downtown Los Angeles
October 6, 2001

INSIDE THIS ISSUE

SIMPLE WISHES TAKE FLIGHT

ALS Patient Given Copter's Lofty View of Coast

BY JASON GEWIRTZ, PRESS-TELEGRAM—Hose Fortuné had a simple wish.

He wanted to ride in a helicopter. And he wanted to ride up the coast of California.

But the logistics of such a flight weren't so simple.

ALS, also known as Lou Gehrig's Disease, has robbed the 41-year-old former football player of most of his movement and speech.

But Saturday, April 14th, with the help of [The ALS Association's Los Angeles Chapter's Simple Wishes] volunteers from Rancho Los Amigos National Rehabilitation Center in Downey, Fortuné got to take his flight out of Long Beach airport.

"This was the day he's been waiting for a couple of weeks now," said Special Miller, Fortuné's nursing assistant.

The Simple Wishes program teams occupational therapists with ALS patients to help the patients complete a special project of their choice. The projects are often something that the patients either can't or won't ask their care providers for help completing.

Simple Wishes began as an idea of [Rancho Los Amigos occupational therapist] Barb Phillips, who helped her father, an ALS patient, complete a desired project — helping him winterize his home in New York.

"He was completely different after that," she said.

Saturday's wish was one of the more ambitious the program has filled to date.

Fortuné, who lives with his wife and 3-year-old daughter, wanted to take a helicopter ride up the coast. He and his wife made a similar flight years ago off Santa Catalina Island.

Fortuné was diagnosed with ALS, a progressive neurological disease in 1992.

While he ran a scaffolding company at the time, Fortune was once a wide receiver for the San Diego Chargers.

Kevin Eastman, who flies helicopters for Rotor Aviation out of Long Beach Airport, said he volunteered to pilot the flight because his wife's grandmother died of ALS.

Fortuné's flight was the 19th wish granted, reported Molly Rockey, the ALS Association, Greater Los Angeles Chapter, Director of Volunteer Services. [Rockey explained how she was told of Barb Phillips idea her first day on the job at the ALS

Continued on page 5

Simple Wishes volunteers from Rancho Los Amigos Rehabilitation Center with Hosea Fortuné (center) and his mother Joyce, third from left.

SCANNING A HEALTHCARE OPTION FOR SENIORS

BY ANN VER PLANCK, DIRECTOR OF PATIENT SERVICES—My article this month only applies to people who are 65+ and have Medicare Parts A and B.

I am writing this month about SCAN™. SCAN™ is an acronym for Senior Citizen Action Network, and it is what is known as a social HMO. Medicare has chosen four HMOs in the country to carry out a pilot project, and SCAN™ is one of the four that were chosen for this project. The purpose of the pilot project was is to give seniors additional benefits so that they might continue to live independently in their homes rather than having to move to a nursing home care.

> **…for families living with ALS, this might be a good alternative you can consider, since it will provide you with additional Medicare benefits at little or no cost.**

In my opinion, these extra benefits are what make SCAN™ an HMO to consider when you are looking for medical care. Those who qualify for the program within SCAN™ program called Independent Living Power™ are eligible for up to $625 worth of extra benefits. Some of the benefits require a co-pay, and some come out of the extra $625 without co-pay. The benefits can include, but are not limited to: in home custodial care, meals on wheels or frozen meals delivered to the home, free incontinent supplies and nutritional supplements (with physician prescription), and respite care, to name a few. Also, a person can get up to 14 days of custodial care, or 7 days of respite care in a nursing home every 60 days as appropriate.

Let me give an example of how this has helped Jim and Sally Williams, a PALS and his wife. Prior to joining SCAN™, the PALS' wife Sally was providing all Jim's care. She also had health problems, and was finding it more difficult to do all the things required to keep their household running smoothly.

I suggested they consider SCAN™ because of the extra benefits. At first they were reluctant, but finally decided to give it a try. Since that time, about 6 months ago, all of them have only had positive things to say about SCAN™. SCAN™ has benefitted them in three specific ways. First Sally no longer has to prepare meals, because they receive frozen meals delivered every 2 weeks. Just that alone gave her increased energy. They are also entitled to in -home personal care and homemaking, and can receive these services several times per week. Finally, they take the SCAN™ taxi to medical appointments for free.

Because of SCAN™ taking care of these three important areas in their lives, the Williams have more time to enjoy things with each other. Without fail, whenever I call them on the phone, Sally always has a new, wonderful story to tell me about how SCAN™ has changed their lives.

However, SCAN™ may not be for everyone. If your doctors are not on a panel with SCAN™, you will have to switch health care providers. This was the case with the abovementioned aforementioned couple. But, what we did was to get, so we got a referral from their current doctors about doctors who are on the SCAN™ panel. In that way, we were able to at least get them a recommendation about another. We did this in hopes of finding a SCAN™doctor who would perhaps approach their care in a way similar to their current doctors. Also, you do have to have approval for many of the services before receiving them, and that sometimes takes time.

Now, as some of you may know, I did work for SCAN™ for about 8 months before joining the ALSA GLAC staff as a Case Manager. But, I receive no remuneration if you decide to join SCAN™. Also, I think all the families with whom I have talked with about SCAN™ will tell you that I present the information in an objective way, and I have never pressured a family to join SCAN™.

The good thing is that for families living with ALS, this might be a good alternative you can consider, since it will provide you with additional Medicare benefits at little or no cost. If you would like to receive more information about SCAN™, all of the Case Managers can arrange for a packet of information to be mailed to you. Just give Ferne Hayes a call at (626) 449-0605 and she will let us know that you are interested in more information about SCAN™.

NAVIGATING THE INSURANCE AND PUBLIC BENEFITS SYSTEMS

BY JOHN JONES, MFCC, SUPPORT GROUP LEADER—One of the most frustrating and time consuming chores persons with ALS and their caregivers have to cope with has been accessing and navigating the insurance and public benefits systems. I've heard a group member say: "A person with this disease needs at least two people—a caregiver AND an advocate to deal with the insurance company and the government." As I looked around the room I noticed the other group members nodding in agreement. With this in mind, the following is a fact and tip sheet, along with a few phone numbers and websites that may be helpful.

Public Benefits – Facts & Tips

State Disability Insurance (SDI): SDI is a short-term financial assistance program for the disabled. This is an entitlement program, meaning you must contribute to SDI prior to collecting from SDI. Your contributions must be recent, and you must be employable (working or looking for work) when you become disabled. The weekly award amounts vary from $50-$490, or approximately $25,980 per year, maximum. You may collect up to 52 weeks worth of benefits. The award amount is based on your past 18-month work period. You may work part-time and collect SDI if your part-time status is due to your disability. A doctor's statement certifying your disability is sufficient to start a claim. Application process time is 2-3 weeks.
Web Page: www.edd.ca.gov

Social Security Disability (SSD, SSDI, Title 2, SSA): SSD is a federal program providing long-term financial assistance. It is your retirement fund, but you may collect early if you are disabled. This is also an entitlement program, thus your award amount is based upon your contribution. Award amounts vary due to length of work history and how much has been paid into the program. All awards will be calculated on the past definition of "disabled," this means that your disability must keep your from working for at least 1 year. SSD has a 5-month wait period from the first day you stop working due to your disability. You cannot receive checks until the sixth month. There is a 3-4 month application process time, and you cannot file an application until you have stopped working. You can also be given a Medicare option.
Web Page: www.ssa.gov

Supplemental Security Income (SSI, Title 16): SSI is also a long-term financial assistance program under Social Security. It has dual criteria: disability and financial need. This program is designed to aid those with lower incomes and limited resources. Resources value cannot exceed $2000 (1 home and 1 car are excluded). Resources include checking and savings accounts, stocks and bonds, property, and life insurance/burial plans with a cash value. SSI will pay up to $712 a month, and includes Medi-Cal benefits. Application process time is 3-4 months.
Web Page: www.ssa.gov

Medi-Cal: Medi-Cal is public medical assistance or government health insurance. It is a state-funded program administered through the county's Department of Public Social Services (DPSS) offices. This program is based on disability and financial need. There are income and resource limitations (identical to SSI). Medi-Cal covers a broad range of services: doctor/dentist visits, X-ray/lab work, prescription drugs, eye care, hearing aids, medical supplies, hospitalization, hospice care, mental health services, chiropractic services, and some skilled nursing home health care. A limited amount of treatment medical sources accept Medi-Cal, (private doctors/hospitals), but all county facilities will. Application takes 45 days to process.
Web Page: dpss.co.la.ca.us

Following is a fact and tip sheet, along with a few phone numbers and websites that may be helpful.

General Relief (GR, Welfare): GR is a financial assistance program for low income individuals with extremely limited resources. Criteria for eligibility are: (1) monthly income must not exceed $611, and (2) other resources must not exceed $50 (a car valued at $4,650, and home valued at $34,000, are excluded). This federal and state funded program is administered by county DPSS offices. Effective 2/1/98, general relief recipients will only be able to receive financial assistance for 5 months in any given 12-month period. Applications take from 3 weeks to 45 days to process. Claimant is eligible for food stamps.
Web Page: dpss.co.la.ca.us

Food Stamps: Federal and state food assistance program for those with financial need. Identical financial and resource limits as SSI and Medi-Cal. Program will pay up to $115 per month.
Web Page: dpss.co.la.ca.us

In-Home Supportive Services (IHSS): This federal program provides non-medical assistance for

Please see *Navigating* on page 9

FREEDOM OF SPEECH

BY LINDA MADOLE, DIRECTOR OF AUGMENTIVE COMMUNICATION—I would like to share a letter that was written to the augmentative communication department. The letter is from a PALS who received a computer-based augmentative communication device from our loan pool. She writes:

"Just a note to express my appreciation for giving me back my voice and my hands. I truly enjoy my partial independence!! My family says I am hooked, because the very first day I received the computer I stayed up until 2:00 a.m. I am so grateful to the ALSA for their generous help."

The types of devices that we have available in our loan pool are divided into two categories: dedicated devices and multipurpose devices.

This is just one of many PALS who has regained this most valuable ability to communicate through the use of augmentative communication devices provided by the ALSA/GLAC Augmentative Communication Loan Pool. You may be wondering just what exactly "augmentative/alternative communication" really is. In terms of people with ALS, it is a means of communication designed to help individuals whose traditional methods of communication have been compromised or diminished completely (i.e., speaking and writing).

The types of devices that we have available in our loan pool are divided into two categories: dedicated devices and multipurpose devices:

Dedicated devices produce synthesized or digitized speech output. They are designed specifically to "talk" for the PALS during face-to-face communication with others. Generally, the PALS types in a message on the device, and with special software, it will relay what was typed in. Many of these devices have specialized features to accommodate the PALS' specific needs. For example, a switch can be used with some devices, in exchange for the keyboard, when a PALS cannot use his/her hands. PALS may even be able to use their own telephone!

Multi-purpose devices (computer-based) use regular microcomputers, laptops, or personal computers with special software in order to communicate as one would with a dedicated device. In addition, it can be used to accomplish tasks that one does on a computer (i.e., e-mail friends, access the Internet, play games). These devices also have specialized features to accommodate PALS with specific or changing needs.

I hope this information is helpful to PALS and CALS who are thinking about alternative methods of communication. I hope the above letter will be an encouraging and inspiring testimony to all! If you would like more information on how to access our loan pool, feel free to call Linda Madole at: (310) 514-8228 or via e-mail at: lindamadole@home.com.

FROM THE EXECUTIVE DIRECTOR...

BY DEBI KLEIN—The Chapter 2001 events have been launched with great success! The Membership Appeal, authored by "ER" Actor Paul McCrane, has garnered much attention and support. The Wine Affair on March 29 was a truly memorable evening, highlighted by the fine wines of Mendocino County and tours of the Skirball Cultural Center's Exhibit "A Stitch in Time by Judy Chicago and Friends." At this time I have the pleasure of thanking our Wine Affair Sponsors — Lockton Insurance Brokers, Rasmussen Foundation, LEI — Mr. and Mrs. Melvin Geliebter, Carol Anne Econn, Mrs. Robert Strub and Family. We are truly grateful for your kindness and support.

The Greater Los Angeles Chapter is looking forward to a myriad of exciting events and programs. As you peruse this newsletter, please note the upcoming educational symposium, Golf Tournament, Tea and Fashion Show, and Diamond Walk — Downtown.

Our Chapter is also excited about the addition of new staff. Please join me in welcoming Ann Ver Planck, formerly a Chapter Case Manager, to the position of Director of Patient Services and Janet Yamanishi to the position of Case Manager. We are proud of the developments with in the Patient Services programs look forward to the leadership and direction that Ann and Janet will provide to our PALS and their families.

Thank you!


Debi Klein, ED

MY SPECIAL "PAL"


L to R PALS Eleanor Verdi with pals Pat Conway and "Klutie" the dog

BY PALS ELEANOR VERDI—"People helping people" is a cliché that I have heard for many years. Because I was so busy raising a family and working full time, I was never one of those people who took the time to help others. Now that I am living with ALS, I find that I need help and rely more and more on the kindness of others.

I found myself on a road to a wider world one day back in August, when I called Ferne Hayes at the ALS Association, Greater Los Angeles Chapter, with a request – could they please locate an automatic page turner to help me read. Feeling bold, I also asked if there was any way to find someone to come to my house to teach me how to use the computer my daughter had given me. I had never used a word processor before, and found it overwhelming to think of learning to use it all on my own. Ferne made a phone call to the Chapter's volunteer coordinator, Molly Rockey. Molly had been in touch with a lady who was looking for someone who needed a "computer coach." She was retired from Litton Industries, and had a strong computer background. In a short time, my special pal, Pat Conway, made her way to my house and into my life.

We started slowly, with the agreement that Pat would come to my house on Thursday afternoons, just for an hour. Sometimes we would work for just one hour, sometimes two or three. The time just seemed to fly when we were together. Since I can no longer use my hands, Pat introduced me to the "task bar" which I use with my feet instead of my hands. I am now sending e-mails and voice-mail (which we're still perfecting), I'm banking on line, creating grocery lists, surfing the net, sending greeting cards (animated and with music!) to my friends and family. How nice to be able to send a birthday card with my own special message whenever I want. The computer has certainly opened up my world!

Another way I'm connecting is through a computer program offered by "Women of Faith," that has me reading the Bible straight through in one year! Just goes to show how one thing can lead to another. I am constantly surprising my family and myself. My newest endeavor is learning to play the harmonica! Pat's husband, Jack, is involved in this production. He has created a special harmonica stand that rests in front of the computer, and allows me to make music while I turn the pages with my foot on the taskbar. To my great good fortune, Pat and Jack even donated an old computer of theirs for the harmonica program that I downloaded from the Internet with the help of Jack Earl. My dog, Klutie, loves it when I play, and even "sings" along with me!

I have learned so much in such a short time, and I now realize that there is always something I CAN do. I feel very blessed! There are still many places I would love to go, and because of the skills I now have, I know there is no limit to where the computer can take me. I give my special thanks to Pat Conway, my special pal, for all the time she has devoted to me. The pals for PALS program has changed my life!

Simple Wishes, from page 1

Association. "I just knew by the name "Simple Wishes" that this was a program that, if given wings, would touch many lives. The Los Angeles Chapter has worked very hard to create the vehicle where volunteers and people with ALS could be matched and dreams could be realized", Rockey said.]

Previous wishes have included a love letter to a family member, searches for lost friends and neighbors,[the trimming and feeding of a rose garden], and a man surrounded by female caregivers who wanted a male buddy to watch a ballgame with him.

Rockey said ALS chapters in Seattle and New York have expressed interest in the program.

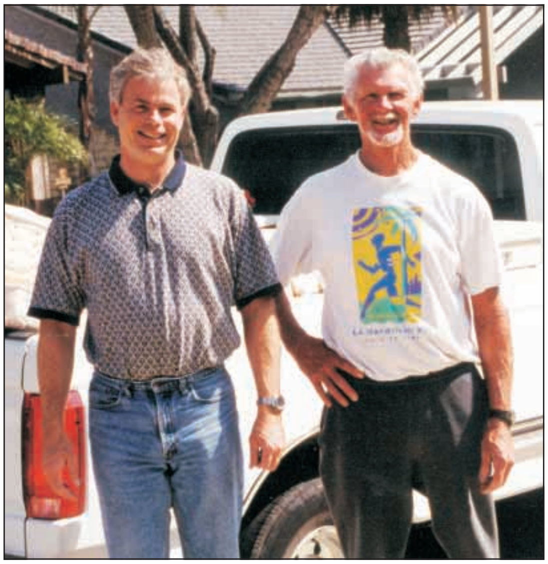

L to R. Kevin Eastman (pilot), Hosea, Barb Phillips, Simple Wishes volunteer Amy Schmidt and Molly Rockey

BETTER THAN MONEY CAN BUY


L-R: Cheryl Terry, our editor with Molly

BY MOLLY ROCKEY, DIRECTOR OF VOLUNTEER SERVICES—There are some jobs that can only by done by a person with their heart in the right place, or require a dedication that comes from compassion built on experience. There are some tasks that inspire us to help regardless of personal inconvenience. The volunteers of the Greater Los Angeles Chapter have proven that they can rise to the task, whatever it is, and do so, over and over again. These past few months we have been fortunate to have an incredible group of people set aside time from their busy schedules to answer our many calls for help.

Cheryl Terry, our new newsletter editor, comes to us from Pepperdine University. Many of you were fortunate to meet Cheryl at the Wine Affair at the Skirball Cultural Center on March 29th. She acted as "roving reporter" and photo assistant, moving among the crowd and gently asking questions, digging deeper, discovering why so many people came out on a Thursday night and fought the rush hour traffic to volunteer their services and support our Chapter's fund-raising efforts. Her enthusiastic report of the event can be found on page 9.


Equipment Loan Pool volunteers
Steve Rockey and Jim Willis

Anne Novack and Kathleen Miller formed their very own "Medocino Decoration Committee" and unleashed their creative talents by adding festive touches to the silent auction tables and securing an incredible array of "grape themed" balloons. Their personal touches were evident through out the room. Anne and Kathleen have volunteered to bring their combined talents to the July 23rd "Tip Your Hat to Fashion and Friends" event at the North Ranch Country Club. We look forward to an elegant and fun-filled afternoon.

It appeared the Equipment Loan Pool was going to have to cancel a much-needed pickup one recent Saturday. Our firefighter with the "big" truck got an emergency call to report to the fire station at the same time he had agreed to move a heavy electric bed from Westlake Village to Reseda. Not to worry. A few phone calls later, two fine men were willing to drop their plans for a few hours and help out. Thank you, Jim Willis and Steve Rockey, for your flexibility and smiles. The bed you picked up created breathing room in a crowded bedroom for one PALS, and gave another PALS the ability to finally get a good nights rest in a bed that can better accommodate her needs.

Pepperdine University students Chris Schady, Ilinca Stanescu, Grant Jantzer, Tony Prakash and Devin Pierenze, under the guidance of Dean Jim Goodrich, have put together a major piece of work for our October 6th Walk-A-Thon. We thank you all for your hours of hard work.

The National Charity League and the Goebel Senior Center continue to take on even greater tasks as our mailing list expands and number of events we hold grows. Leaders in both organizations are stepping up and offering help in many ways. We rely on their energy and positive attitudes to get many tasks completed.

For every phone call made, box lifted, envelope stuffed, balloon filled, letter typed, article written, home visit made, Simple Wish fulfilled, mile driven, committee and Board meeting attended, photo taken, good idea shared, sponsor secured, lunch provided, promise fulfilled, sentence composed, for helicopter rides and recipes downloaded, for every donation of money, time, energy and talent – WE THANK YOU! What you bring to the ALS Association is priceless. You wear your hearts up front, your compassion for others touches the lives of people you will never know, and your ability to complete jobs with excellence and cheer prove some work can only be done with volunteer energy.

LOOK AT WHAT I HAVE TO SAY...

Using writing and alphabet boards to communicate

BY CARLENE MACBRIDE, MA, CCC-SLP AND BARBARA PHILLIPS, MS, OTR—As ALS progresses, talking may become less of an option for communication. Speech may become extremely difficult to understand, or too fatiguing to use. In previous articles, CART has discussed strategies and technology that may help you to use speech effectively for as long as possible. When those suggestions are no longer helpful, writing and alphabet boards may be considered. Which option is best for you can be determined through an evaluation by your speech pathologist and occupational therapist.

Writing

Writing may be used to supplement only those spoken words that are not understood, or can be used in place of talking. This all depends upon how much your speech has changed. You can first speak your message, then write down only those words the listener is not understanding. Sometimes it only takes a couple of letters for the person to get the gist of your message. You can also write all of your thoughts down if your speech is not understood at all. This may occur when communicating with certain people, such as your grandfather who has a hearing loss, or in situations where there is a lot of background noise, such as a party or outdoor mall. Writing is also helpful because it takes less effort and is less tiring than speaking.

There are various things you can use to write your messages on. Some people like to carry a small note pad that fits easily in a shirt or pant pocket. For other people, a larger notebook or clipboard works well because they are able to write using large print if they communicate with people who have trouble seeing the letters. A dry-erase board is easy for some people because they are able to wipe the board clean after each message, without needing to turn pages or worry about running out of paper. What you select will depend on your needs, and what works best for you.

Because writing is not like talking, there are some drawbacks. For example, it is difficult to communicate on the phone or talk to a lot of people at one time when you use writing. If you need to talk to small children or people who are unable to read, writing will not help. However, for most situations it is extremely helpful and convenient. Writing utensils can be inexpensive, light weight to carry, and writing allows you to talk with people while keeping conversations fairly private. In addition, writing messages does not require a lot of instruction for use.

Being able to write is also dependent on your physical abilities. For some, holding a pen can be difficult. In stationary stores you can find different adaptations that making holding a pen easier for minimal cost. Foam grips slide over thin pens and allow you to hold the pen where it is most comfortable. Rubber grips with indentations to position the fingers are also available. Some people find writing with a pencil is easier because it offers some resistance to the paper, and others find writing with a rolling marker easier because it offers less resistance than a standard pen. There are also many new Aergonomic@ pens on the market. These should be tried before purchase, because although these pens are thicker or the grip cushier, they tend to be heavier than standard pens, and more difficult to manage. These decisions can be made through trial and error, or with the guidance of an occupational therapist.

Alphabet Boards

If writing is too difficult, an alphabet board may be an option for you. Instead of writing words or full messages, you can point to letters of the alphabet on a board to spell out the message. Often, you will just need to point to the first few letters of the word in order to be understood.

There are also some problems that may arise with use of alphabet boards. For example, some people may have difficulty following along and remembering the letters that you have pointed to. This is particularly common with people who have never interacted with individuals who use communication boards. It can also be difficult for some people with limited vision to see the letters on the board.

When those suggestions are no longer helpful, writing and alphabet boards may be considered.

Pointing to the letters on an alphabet board may also require positioning the board in a way that is easy for you to reach and also easy for the listener to see. The letters must be a size that is easy for you to point to, and not so close together that the listener misreads which letter you have selected.

Here are a few suggestions to make using an alphabet board easier and more effective:

Place the board on your lap or in a position that is easy for you to point to, but also where the listener can see the letters.

Suggest that people write down the letters as you point to them. This helps listeners to spell out your message.

Tell the listener that it is okay to guess your message. This will

Please see *Look* on page 10

An Affair

A Mendocino moment – we welcome you to the "Wine Affair"

BY CHERYL TERRY—Although it didn't star Cary Grant or Deborah Kerr, the 2001 Wine Tasting Affair did draw the likes of William Ragsdale, star of TV's "Grosse Pointe," and former Dodger Wes Parker. The March 29th event was a fundraiser for the Greater Los Angeles chapter of the ALS Association, and was a great success. Over 200 guests, volunteers from the National Charity League, and thirteen wineries from the Mendocino Winegrowers Alliance attended the Wine Tasting Affair.

Upon arriving at the Skirball Cultural Center, attendees were greeted by the team of tireless ALS volunteers and the melodious sounds of the Calabasas Chamber Orchestra. The atmosphere alone could have made the event a success; the beautiful array of hors d'oeuvres was highlighted by bouquets of balloons in the shapes of wine bottles and bundles of grapes; and the souvenir wine glasses honoring donors made the perfect party gift. The string quartet was soon accompanied by the joyful conversations of both reunited and newfound friends.

PALS Ruth Kaufman shares a moment with Molly Rockey

William Ragsdale, well-known actor and loyal friend of the Los Angeles chapter, served as Master of Ceremonies for the evening, enlivening the crowd with his witty humor. "My favorite aspect of this event?" he pondered, "the wine!" On a more serious note, Ragsdale, whose mother died from ALS in 1996, said, "The ALS Association was the only resource available when my mom was going through the disease. They were so supportive; they enabled my mother to live much longer, and in a way that she otherwise might not have been able to." Carl Frova, an ALS patient, shared this thought, saying that ALSA has provided him not only with valuable information, but also with a great deal of adaptive equipment that allows him to live more comfortably with ALS. Frova said that he appreciates the ALS Wine Tasting Affair because it "gives people the opportunity to come into a comfortable and fun environment, while giving financial support so we can lick this thing."

Guests with wine lover Larry Twersky (2nd from left) shares a toast with friends.

The affair was complimented by Judy Chicago's "Resolutions: A Stitch in Time," a collection of painted and needlework images that reinterpret traditional proverbs and adages for contemporary society. Private tours of the exhibit were given throughout the evening by museum docents, enabling guests to gain a deeper understanding of the artwork. The ideas and concepts woven into Chicago's work were remarkably appropriate for the ALS fundraiser.

Guests tour the exhibit by Judy Chicago

to Remember

The pieces are based on seven basic values: family, responsibility, conservation, tolerance, human rights, hope, and change. The exhibition resulted from the collaboration of sixteen talented needle workers, in addition to Chicago herself. This emphasis on teamwork, and the stress placed on the values of hope and change, are not only representative of Chicago's message, but are also the keys to winning our fight against ALS. These uplifting messages added to the excitement of both the event itself, and to the anticipation of the positive effects that will result from the funds raised that evening.


The Frova Family

Another light of hope during the evening was an inspiring speech by Founding President and CEO of the Skirball Cultural Center, Rabbi Uri Herscher. Rabbi Herscher commended PALS and volunteers alike, saying, "What we have in this room are the real heroes." He went on to discuss our personal responsibilities in life, addressing the fact that there are, indeed, tangents in the road that we cannot foresee. We can, however, "judge, when a tangent is taken, if it is for good or for ill. If it is for good, we celebrate the goodness, if it is for ill, we make it less ill." His moving speech concluded with his pledge to donate $5,000 annually to the Greater Los Angeles chapter of ALSA.

The success of the event was a result of the hard work of many, and was especially aided by a public service announcement aired on 790 KABC Talk Radio. Thanks to their efforts, the efforts of the volunteers, and the many guests in attendance, the 2001 Wine Tasting Affair brought tremendous hope to Los Angeles area PALS. With the continued success of such events, we will be able to, in the words of Judy Chicago, "Turn over a new leaf," in the fight against ALS.


L to R Long Term Supporters Shirley and Stan Cowen, Andrea Green, Pat Snyder and Carol Econn (past president)

LOCKTON
Lockton Insurance Brokers, Inc.

C.A. Rasmussen, Inc.
C.A. Rasmussen Company
West Pointe Homes Inc.
D & L Equipment Co.
Carco Equipment


Calabasas Chamber Orchestra adds a touch of elegance to our special event.


Dr. Uri D. Herscher, President of the Skirball Cultural Center, shares words of wisdom with our guests.

EYEING SSI

BY PEDRO LOZA, CASE MANAGER—In a previous article, In-Home Supportive Services (IHSS) was explained. We will now explore another Social Security based program called Supplemental Security Income (SSI). This program pays monthly checks to people who are 65 or older, blind, or have other disabilities, and who don't have many assets or much income.

Being "disabled" means that you have a physical problem that not only keeps you from working, but also is expected to last at least one year. SSI isn't just for adults; disabled and blind children are also eligible. People who receive SSI usually get food stamps and Medicaid (which helps pay medical bills). Your eligibility for SSI also depends on what you own and how much income you have.

"Income" is the money you have coming in, such as wages, Social Security benefits, and pensions. Income also includes non-cash items you receive such as food, clothing, or shelter. If you are married, Social Security also looks at the income of your spouse and things he or she owns. If you are a sponsor alien, Social Security also looks at the income of your sponsor and what he or she owns. The amount of monthly income you can have and still qualify for SSI depends partly on where you live. If you feel that you may qualify for this program please contact Social Security at 1-800-772-1213.

EYEING SSI

PEDRO LOZA, MANEJADOR DE CASOS DE ALS—En el artículo pasado los servicios de apoyo caseros (IHSS) fueron explicados. Tomaremos una medida más lejana y explicaremos otro programa basado del Seguro Social llamado (SSI). SSI es la abreviatura de Ingresos de Seguridad Suplemental. Este programa paga cheques mensuales a personas de 65 años de edad o mas, ciegos, o con alguna minusvalia y quienes poosen de poco o tengan bastantes ingresos.

Minusvalia significa que tenga un problema fisico que lo mantenga sin poder trabajar y que dure por lo menos un año. SSI no es solo para adultos. Los cheques mensuales pueden otorgarse tambien a ninos minusvalidos y ciegos. Gente que adquiere SSI usualmente recive estampillas de comida y Medicaid. Medicaid ayuda a pagar las cuentas de doctores y hospitales. Si usted puede adquirir SSI tambien depende de lo que posee y cuantos ingresos tenga.

Ingresos es el dinero que recive de su salario, beneficios del Seguro Social y pensiones. Ingresos tambien incluye cosas no monetarias como comida, ropa o refugio. Si es casado el Seguro Social verifica los ingresos y cosas que su pareja posee. Si usted es un patrocinador de un extranjero, el Seguro Social tambien verifica los ingresos de su patrocinador y los que el o ella posee. La cantidad de ingresos que usted tenga cada mes y que puedad recibir del SSI depende en parte de donde usted vive. Si usted cree que califica para este programa porfavor hable con el Seguro Social Al 1-800-772-1213.

Look, from page 7

speed the communication process and make it more energy efficient for you.

Both writing and alphabet boards can be used to assist you in communication. Your current abilities and needs will help determine which option is best for you. In some cases, PALS will utilize both approaches, depending upon the situation. Consulting a Speech/Language Pathologist and/or an Occupational Therapist can assist you in determining which approach is optimal.

An article in the next issue of the ALS Messenger will discuss the use and variations of communication boards depending on your needs and abilities.

Carlene MacBride Yonemori, MA CCC, is a Speech/Language Pathologist, and Barbara Phillips, MS, OTR is an Occupational Therapist at the Las Floristas Center for Applied Rehabilitation Technology (CART) at the Rancho Los Amigos National Rehabilitation Center.

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LOS ANGELES CHAPTER

LIFE IS MORE THAN BREATH

BY LOTHAR DELGADO, CASE MANAGER—ALS has been the messenger of many important life lessons since I began working with PALS and their families over two years ago. Extraordinary human beings have lead me to reevaluate the meaning of a "life worth living." It is a privilege to provide services as a Case Manager with the LA Chapter.

I came in contact with my first ALS patient in my former position as a Hospice Social Worker. Her once "chronic" condition was diagnosed as "terminal" when she could no longer be sustained on a BiPap. She had made the conscious decision to go no further. One of the rare familial ALS cases, she had seen two older siblings and a twin sister succumb to the disease, and she decided against a tracheotomy and ventilator. Her last weeks were spent with friends who wrote letters from her to her three young children. They would be delivered on the important occasions of birthdays, graduations, weddings, and parenthood; occasions that without these letters, she knew she would not share with them.

A bit further down the road I met another extraordinary woman, who taught me that she "was NOT terminal;" she was living each day to her fullest, with gratitude and faith that her spirit could overcome her physical limitations. Her courage to live with such a positive attitude gave me a model for coping with this disability. She continues to be an inspiration to her family and friends.

A recent visit to a PALS in a skilled nursing facility, helped me to see how the profound will to live can exist even in the face of paralysis and dependence on a ventilator. Using an alphabet board and eye blinks, she told me what was important to her: friendships, films, literature, and communication. Her main worry was that she would not be able to use her computer when she returned home. It was so important to her to communicate in this way. We were able to secure an evaluation, and have found out that her insurance will cover the cost of the equipment she needs.

I used to think that life was breath. That was a nice philosophy until I met people challenged by this daunting disease. Life has a meaning that goes far deeper than breath itself. Perhaps life's meaning is unnamable, but it seems to me that it is the quest that keeps us coming around until all of our lessons are learned.

Navigating, from page 3

disabled persons with personal, domestic, and financial needs. Personal care includes dressing, feeding, and cleaning. Domestic services include household chores and food preparation. The financial need and limited resource criteria are identical to those of SSI. All IHSS recipients qualify for Medi-Cal. Amount of hours awarded for services is determined after an in-home assessment.
Web page: dpss.co.la.ca.us

Cal Works (California Work Opportunities and Responsibility to Kids), formerly AFDC (Aid to Families with Dependent Children): Federal and state financial assistance for families in need. Financial need must be extreme and family resources cannot exceed $1000. Must have minor children. Benefits are based on number of children. New Cal Works regulations stipulate 2-year cutoff, new work requirement, and a 5-year lifetime maximum receipt of Cal Works monies. Additional children born into the household after Cal Works program is initiated will not trigger an increase in monthly Cal Works payments. Claimants also qualify for food stamps and Medi-Cal. Application can be made at DPSS, and takes 1-2 months.
Web Page: dpss.co.la.ca.us

An acquaintance who worked for one of the HMO's once told me that the most effective way to receive the services needed is to show up at the front door of their administrative offices. The Department of Managed Health Care (DMHC) regulates and licenses HMO's and PPO's, and is designed to have a patient complaint process to assist with complaint resolution. The procedure is as follows:

The consumer must file a formal complaint with the HMO. If the issue remains unresolved in 30 days, then a complaint can be filed with the DMHC.

A complaint form can be obtained by calling (888) HMO-2219, or by downloading it from *www.hmohelp.ca.gov* or *www.dmhc.ca.gov*.

This form is then mailed with supporting documentation.

Finally, if you are dissatisfied with your insurance plan's benefits, The Consumer Hotline for the Department of Insurance may be useful. The phone number is (213) 897-8921.

Please Note: This information is provided solely as a courtesy, and should not be acted upon without specific consultation with the agency involved.

MOVING ON...

BY LISA WEINER, PH.D, DIRECTOR OF PATIENT SERVICES—After six wonderful years working with the Greater Los Angeles Chapter of ALSA as the Director of Patient Services, I will be leaving this position.

I have had the opportunity to work with an unbelievably dedicated and compassionate team of professionals in the patient services department, and I am grateful for the experience of working together to assist the ALS community. Our chapter has grown a tremendous amount since the day I first walked into the chapter office. Back then, we had four people on a steering committee led by Carol Econn, wonderful volunteers such as Ferne Hayes and Chaz Shields, and a few consultants. The Patient Services Department was comprised of a few small support groups, a modest equipment loan pool, and a very limited augmentative communication loan pool.

Today, we have an unbelievable Executive Director, Debi Klein, who performs miracles everyday in her fundraising efforts and leadership of the chapter. Our Board of Directors has grown to fourteen professionals. Closest to my heart however, is the expansion of the Patient Services Department. This department now includes four large and cohesive support groups (including a monolingual Spanish group), an equipment loan pool with more than 3,000 pieces for loan, an augmentative communication loan pool that has increased it's productivity by more than 600%, and a new case management department consisting of three superb professional case managers.

The chapter is the strongest it has ever been, and I don't think I could not have chosen a more appropriate time to say goodbye. I have truly enjoyed working with PALS and family members over the years. I admire the strength and endurance of the families I have worked with, and feel my life has been enriched by getting to know them.

I am passing the torch to my successor, Ann VerPlanck, in whom I have the utmost confidence. She, along with Debi Klein and the rest of the Patient Services staff, will continue to fight beside you, not only for a cure, but also for the improvement in the quality of life for persons with ALS. As always, you will remain in my thoughts and in my heart.

A message to Lisa Weiner from the Greater LA Chapter:

Lisa, you have brought your knowledge, your talents, and your true concerns for those persons afflicted with ALS to our Chapter, and we will be forever grateful to you for all that you have done to ensure that our Chapter provides a high level of service and dedication to our Community. Under your guidance we have developed a "premier patient services program" and will continue this philosophy of excellence as we look toward the future. Thank you so very much. We will miss you.

A NEW MEMBER OF OUR COMMUNITY: JANET K. YAMANISHI

As the newest case manager to join the Greater Los Angeles Chapter of The ALS Association, I would like to take this opportunity to introduce myself. I bring to the position over 25 years of diverse health care experience, including direct patient care and administrative responsibilities, as well as a knowledge of the special needs of patients and their families, and support services available throughout the community.

As I complete my orientation in the months ahead, I look forward to meeting the dedicated staff at both the local and national levels. As I begin my duties as a case manager, I am eager to face the challenges and rewards of working with the ALS community.

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.

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ALSA — LA CHAPTER SUPPORT GROUPS

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 (323) 660-4484, for more information.

May 19 — Presenter: Ferne Hayes, Patient Services, "They Say ALS Has No Pain"

June 16 — Presenter: George Vargas, "Navigating Benefits, Part II"

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) 542-7048 for more information

May 19 (replaces Memorial Day weekend meeting) — Diana Guth, RRT, Topic: Home Respiratory Care

June 23 — Topic to be announced

Monolingual (Spanish) Support Group

Note: New Location City Terrace Library, 4025 East City Terrace Drive, Los Angeles, CA 90063; Third Saturday of each month from 3:00–4:30 p.m.

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

May 12 — Topic: Home Modifications

June 9 — Topic to be announced

Temas y Fechas para el grupo de apoyo

12 de Mayo — Modificaciones para el hogar

9 de Junio — Ba aser anunciado

Westside

American Red Cross Building, VA Grounds, 11355 Ohio Avenue, Los Angeles, CA 90025, Meeting Room 7; 1st Saturday of the Month!

For Information, Contact Support Group Leader John Jones (323) 660-4484

May 5th — No meeting, replaced by "Ask the Experts" Educational symposium in Culver City

June 2 — Emotional Process and Group Support

SAVE THE DATE!

Ask The Experts 2001 for PALS, family members, care givers and health care professionals

Radisson Hotel — Westside
May 5, 2001

Golf Tournament

Northranch Country Club
July 23, 2001

Fashion Show and Afternoon Tea

Northranch Country Club
July 23, 2001

Walk-A-Thon

Downtown Los Angeles
October 6, 2001

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 January, 2001 through March, 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.

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A GROUP EFFORT

BY MARTHA MOWATT—When facing a trial such as ALS, it is normal to feel that others do not understand what you are going through, and cannot relate to your feelings. You may experience a range of emotions, including despair, anger, depression, and others, all of which can make you feel very isolated.

A support group can really help! A support group can bring together people experiencing similar troubles, to share the nature of their trials and the emotions that can result. You may feel that your experiences and emotions are private; perhaps you don't like to discuss your problems with anyone. You may feel that there is little or no point in listening to other people's problems when you have plenty of your own. However, a support group can benefit you in ways that you may not realize. While it is an environment where you can talk about what you are going through, you also learn that you are not alone. There are others in similar situations, and you can learn from one another's physical and emotional experiences. There are many advantages to being part of a support group, including learning how others are coping, gathering new information relating to the issue, and acquiring problem-solving skills. Even more important, however, is the fact that the group becomes an arena for mutual support—you find yourself surrounded by those who not only care, but who also understand and empathize.

The ALS support groups provide an opportunity for PALS, friends, family members, and caregivers, to come together once a month to share problems and solutions, to learn about different topics relating to the disease, and to make new friends. It is never too early or too late to join a support group. ALS is a progressive disease with new challenges emerging everyday. Make use of these support groups to meet others with whom you can share information about how to handle those new challenges. You can help yourself while helping others.

For more information on support groups, please contact the Chapter Office.

EN ESPAÑOL

Cuando pasamos por tiempos dificiles, aveces nos sentimos que nadie entiende lo que estamos pasando o nuestros sentimientos. Aveces hasta hemos proguntado, “Por que yo?” En medio de nuestro enojo, desesperacion, depresion o cual quier tipo de emocion que estemos pasando, nos sentimos solos.

El proposito de un grupo de apoyo es para traer a personas que esten pasando por situaciones similares juntas para compartir nuestras experiencia y nuestros sentimientos. Talvez piense que sus problemas y sentimientos son personales. O puede ser que no le guste hablar de sus problemas con otras personas y menos cuando se trata de personas extranas. Para que se va a reunir con personas para hablar sobre sus problemas cuando usted tiene los suyos. Un grupo de apoyo sirve mas de un proposito. Es un lugar donde uno puede hablar sobre problemas y descubre que uno no esta solo. Hay otras personas en situasiones similares o peores. El bono del grupo es aprender como otros toleran su situacion, informacion nueva relacionada al tema, y como resolver problemas. El grupo es un lugar para dar y recivir apoyo mutuo.

Los grupos de apoyo de la Asociacion ALS proveen oportunidades para PALS, familiares, amigos, y cuidadores que se reunan una vez al mes para compartir problemas y soluciones, aprender informacion sobre la enfermedad, y conocer nuevas amistades. ALS es una enfermedad progresiva que trae nuevos retos. Por que no usar el medio de los grupos para conocer a otras pesonas que si entendien su situacion. Se ayudara a usted mismo mientras ayuda a otros. Sea parte de un grupo.

Para mas informacion sobre los grupos de apoyo por favor comuniquese con su oficina de ALS

FROM OUR PRESIDENT, DR. CECILE FALK

We have been working hard to promote awareness of ALS and the needs of PALS. For an illness thought to be rare, numbers of afflicted people are increasing, and we are fortunate to have the assistance of people out there like you who are generous with your time, efforts and contributions. May is ALS awareness month with a national meeting in Washington D.C. promoting awareness among our nation's legislators and giving those of us working with PALS a chance to meet and share our knowledge. Our Chapter has our annual Ask The Experts Symposium this year, Saturday, May 5, focusing on cutting edge research in ALS being performed through out the country.

We want to take time out to say Thank You to all of our supporters

We are always trying to keep you abreast of what we in the Chapter Office are doing. It is important that you know of our efforts and our plans. Please remember that each one of you, as you read this column, is in the office with us, in our hearts and in our thoughts. As we come to that time of year when we are focusing on ALS education we want to take time out to say Thank You to all of our supporters. We need you, we appreciate you, and we want you to be aware of this. Our scientists are necessary to continue the battle against this illness but your efforts are necessary not only to support this battle, but to give comfort and dignity to the lives of the men and women struggling with ALS. We will be acknowledging our major donors at a post Ask The Experts Reception. But each one of you is a major in this army, in this battle, and we salute you. Thank you for your assistance and please keep in touch with us.

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