ALS ASSOCIATION®
MESSENGER
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A Publication of the Amyotrophic Lateral Sclerosis Association, Greater Los Angeles Chapter

## SAVE THE DATE!

**Wine Tasting Affair**
**Skirball Cultural Center**
**March 29, 2001**

**Ask The Experts 2001 for PALS, family members, care givers and health care professionals**
**May 5, 2001**

**Golf Tournament, Northranch Country Club**
**July 23, 2001**

**Walk-A-Thon October 6, 2001**

## A DREAM COME TRUE

**BY JENNIFER PETRINI**—In February of last year my family received the devastating news that my father, John Petrini, has ALS. The news came as a complete shock to us all, as I don't remember my dad ever being sick. My dad has three daughters; I am the oldest at 25, Lisa is 22 and Angela is 18. After the initial shock of the news wore off, we were able to have some real heart-to-heart conversations with our dad. Somehow through all of the pain he was able to look beyond his prognosis and make the decision to really live his life.

In June, my dad, my sisters and I went skydiving in Peris Valley. It was something that my dad had always wanted to do, but never did. I have to be honest and say that I had never given any thought to jumping out of a perfectly good plane. However, his desire and the knowledge that this would no doubt become a precious memory, nullified any doubts I may have had. Although my sisters and I felt a little queasy by the time we landed on the ground, the look on Dad's face when he landed made it all worth it. I think the smile was still on his face when he fell asleep that night.

In November we got the opportunity to see that smile again. Ever since my dad was a young boy, he has wanted to fly in a biplane. He imagined himself living in some rural town, flying around in his biplane, wearing a scarf and an aviators cap. Although he didn't get a chance to make that dream come true, he came awfully close that day. With the help of my mom, Carol, we were able to make one of my dad's lifelong dreams come true. Although my mom and dad are divorced, they remain good friends and she was the one who helped organize the whole event.

My mom's friends, Mike and Kendel Hanson, own a vintage World War II biplane and, after just one conversation with my dad, Mike promised me that we would get him in the sky. When I got to my dad's house on November 11, I was happy to see that the smile was already on his face. It was a beautiful Saturday morning and as we sat in the backyard I asked him what he was looking forward to the most about the flight. His answer was, "The sound." It wasn't until later in the day that I really understood this.

Since my dad had little strength left in his legs, Mike and some

Continued on page 8

## INSIDE THIS ISSUE

## FROM THE EXECUTIVE DIRECTOR...

**BY DEBI KLEIN—An Exciting Year for the Greater Los Angeles Chapter**

**Debi Klein, ED**

2001 promises to be a year filled with programs, projects and progress for our chapter. We invite you to join us for a variety of upcoming activities:

✦*The Annual Chapter Meeting* and election of officers, Thursday, February 15

✦*Mendocino Wine Affair: Highlighting the wines of Mendocino County* and a special exhibit by artist Judy Chicago, "Resolutions: A Stitch in Time", Skirball Cultural Center, West Los Angeles, Thursday, March 29, 5-8 p.m.

✦*Ask The Experts Symposium*—a focus on current research and trends, Saturday, May 5

✦*The ALSA National Leadership and Advocacy Conference*, Washington DC, May 16–19

✦*The Authentic Golf Classic*, North Ranch Country Club, Monday, July 23

✦*High Tea and Fashion Show*, North Ranch Country Club, Monday, July 23

…and our first Walk-A-Thon, The Greater Los Angeles Chapter Diamond Walk—Downtown, Saturday, October 6.

PALS, families, friends and supporters are welcome and encouraged to be a part of the dynamic events that enhance our chapter and assist us in reaching our goals. Tammy Ennis, Event Coordinator, is enthusiastic about the success and "fun" of these activities and is delighted to share the details with our membership. Are you interesting in planning an event? Please call Tammy at the chapter office (818) 865-8067—new committees are forming at this time.

## THE YEAR AHEAD

**BY CECILE FALK BALSER, CHAPTER PRESIDENT—**Welcome to 2001 and the new millennium. For the staff and volunteers at the LA Chapter let me wish you a happy and healthy New Year with much hope for the ALS Community.

**Molly Doyle, CART (2nd from left) instructs healthcare professionals on a communication device**

We started off the year with a successful educational program on January 13th, "Developing a Subspecialty in ALS", which we did jointly with the UCLA ALS Clinic and Research Center. In attendance were over one hundred healthcare professionals who were able to learn more about assisting PALS and their families. Our next educational program, "Ask the Experts" is scheduled for May 5, 2001, and will focus on the most up to date research in ALS. We will get more information to you, as the program looms closer. It promises to be an exciting and informative agenda with professionals doing cutting edge research in the field.

**Educational Symposium Sponsor Representative Dan Borchers, Aventis Pharmaceuticals, Drs. Michael Graves and Linda Sepulveda, UCLA ALS Clinic, Debi Klein, Executive Director, LA Chapter, ALS Association (r-l)**

On the more playful side we have a wine tasting scheduled for March 29 at the Skirball Cultural Center, and a Golf Tournament, High Tea, and Fashion Show, scheduled for July 23, 2001 at the North Ranch Country Club. On October 6 2001, we will have a Walk-A-Thon, whose route will take us through the newly refurbished areas of historical downtown Los Angeles.

Our tentative agenda is just one way we have of showing you that we are always working for the people living with ALS in the Greater Los Angeles County Area. We are at all times working behind the scenes to provide more services and programs for PALS and their families. I look forward to seeing you at any of our Chapter events and want to encourage you to keep in touch with our dedicated staff and volunteers.

Together, let's look forward to a year of hope and progress.

## 2001 – THE INTERNATIONAL YEAR OF THE VOLUNTEER

Molly Rockey

**BY MOLLY ROCKEY, VOLUNTEER CO-ORDINATOR—**In November 1997, the United Nations General Assembly proclaimed 2001 the International Year of the Volunteer. In the United States, the number of individuals who volunteer has reached almost 56 percent — 62 percent of women volunteer an average of 3.4 hours per week and 49 per cent of men volunteer 3.6 hours per week. In 1998 an estimated 109 million adults volunteered is some capacity. (Source: Independent Sector, 2000) These statistics show how deeply volunteerism is woven into the fabric of our culture.

Newbury Park High School Key Club Volunteers

At the ALS Association Greater Los Angeles Chapter, we experience every day the creative and loving energy of our volunteers and the unique contributions they make to our Chapter, PALS and families. Energy is being dedicated to fund and support the volunteer programs that are already have in place, and we are working to create innovative ways to honor our valuable volunteers and expand our training programs. Looking to the future, our leaders know that as the Chapter grows, our volunteer needs will grow, too.

As we begin 2001, we acknowledge our 214 volunteers who have donated over 1644 hours to the following projects in the past twelve months: Simple Wishes, pals for PALS, serving as leadership on the Board of Trustees and committees, fundraising, monitoring computer sites, providing energy for the Equipment Loan Pool, helping in the office with all kinds of projects, processing newsletters and event mailings, delivering augmentative communication devices to PALS, decorating clipboards and silent auction tables, helping with the office move, creating valentines, assisting at "Ask the Experts" symposiums, proofreading materials, acting as hosts and hostesses at events, writing articles for newspapers and our newsletter, soliciting silent auction items, gathering needed data, entertaining us at the Gala, acting as advocates, folding and taping, stapling and stuffing . . . and much more.

Our volunteers come to us from many places. Some sources are: United Postal Service, the Walt Disney Company, National Charity League, Key Clubs from local high schools, RSVP at the Goebel Senior Center, Volunteer Match, McDonalds, Pepperdine University, Cal Lutheran University, the ALS National Office, Rancho Los Amigos National Rehabilitation Center, retired nurses, Singles Helping Others, and of course our families and friends.

National Charity League

RSVP at the Goebel Senior Center

There is no way we could provide the services we do for our PALS and their families without our volunteers. They make the organization work every day. In this, the International Year of the Volunteer, we thank you, appreciate you and celebrate your willingness to share so much of yourselves.

## CASE MANAGEMENT FOR SPANISH SPEAKING PALS

**BY PEDRO LOZA—**For many people, money becomes an issue when those who we love become ill. Unfortunately many of us are unaware of state programs that provide assistance to low-income families. In-Home Supportive Services (IHSS) is a statewide public program providing personal assistance services to low-income people with chronic and disabling conditions who need such assistance to remain safely in their homes. In Home Supportive Services include chore and house cleaning services, as well as personal care including assistance with eating, bathing, dressing, and using the toilet. IHSS allows consumers to live safely at home, where they want to be, rather than in institutions. The majority of consumers receive services from individual/independent providers who are not employed by an agency. In the independent provider mode, consumers are assured their right to choose their worker and provide ongoing supervision, while the state provides payroll services.

**IHSS allows consumers to live safely at home, where they want to be**

If you feel that you may qualify for IHSS and would like to know more about this program please contact the Case Management Department, through Ferne Hayes (626) 449-0605.

**Translation in Spanish**

**POR PEDRO LOZA—**Para mucha gente, el dinero se convierte en una edicion cuando los que amamos llegan a enfermarse. Desafortunadamente muchos de nosotros estamos inconscientes de los programas del estado que proporcionan ayuda a las familias que estan economicamente bajas. Los servicios de apoyo caseros (IHSS) es un programa publico estatal que proporciona a servicios personales de ayuda a la gente de ingreso bajo y de condiciones cronicas que necesitan tal qyuda de permanecer con seguridad en sus hogares. En los servicios de apoyo caseros incluye lo siguiente; limpieza, cuidado personal tal como ayuda para comer, banar, vestir, y usar la vacinilla. IHSS permite que los consumidores vivan con sequridad en su casa, donde desean estar, mas bien que en instituciones. La mayoria de los consumidores reciben servicios de personas individuales/independientes que no son empleados por una agencia. El modo independiente del abastecedor, aseguran a los consumidores el derecho de elegir a su trabajador y de progorcionar la supervision en curso, mientras que el estado proporciona servicios de la nomina de pago. Si usted siente que califica para estos servicios de IHSS y quisiera obtener mas informacion sobre este programa por favor pongase en contacto con uno de los manejadores de casos para ALSA-GLAC.

## ASSISTANCE THROUGH OCCUPATIONAL THERAPY

**BY JOHN JONES, MFT, SUPPORT GROUP LEADER—**Seeing an Occupational Therapist has been useful to many persons with ALS because Occupational Therapy focuses on those daily tasks of living, such as eating, getting dressed, or work, that give meaning and satisfaction to our lives. Occupational Therapy can help Persons with ALS remain as independent and self-sufficient as possible, given the progression of the disease at the time of the appointment. For example, if a person could no longer turn off the light at night, an occupational therapist may suggest a piece of equipment called a reacher, which would serve as an extension of the person's arm. Another useful tool Occupational Therapists' may suggest is referred to as a sock aide, which can help a person put on socks without having to bend over.

**Occupational Therapy has been helpful … by finding ways to work within each person's individual limitations in order to bring maximum satisfaction and quality of life in daily living.**

One of the goals of Occupational Therapy is to find methods of assisting people in the performance of daily living tasks within each person's capabilities. **So the key here is to recognize and accept our limitations, then ask for help!**

Both of these processes can naturally be difficult for a person with ALS, given a lifetime of independence and self-sufficiency, particularly with such simple tasks that we take for granted. Occupational Therapy has been helpful to some members of the Pasadena Support Group by finding ways to work within each person's individual limitations in order to bring maximum satisfaction and quality of life in daily living.

The information about occupational therapy for this article has been provided by Katie Gundersen, MS, OTR, who will be presenting at the February Support Group Meeting in Pasadena. (See schedule for information)

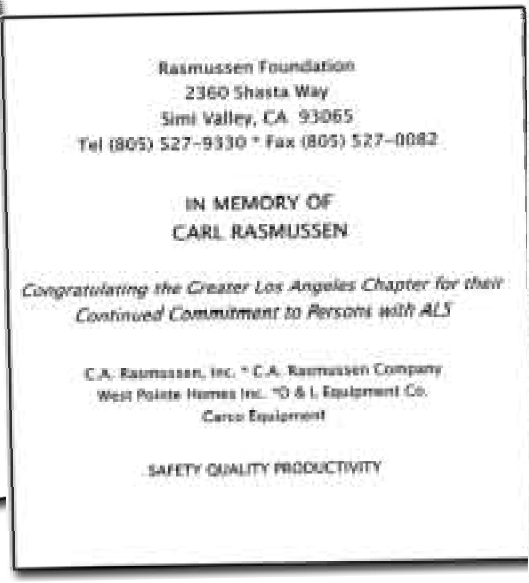
## AUGMENTATIVE COMMUNICATION NEWS

**BY LINDA MADOLE, SLP, DIRECTOR OF AUGMENTATIVE COMMUNICATION—**Happy New Year! For those of you who have not yet heard about the new Medicare coverage for Augmentative/Alternative devices, I have good news, which came to my attention from an e-mail sent by Pat Snyder. The source of this helpful information is Lew Golinker, Director of the Assistive Technology Law Center in Ithaca, New York. In speaking with him, as well as the Health Care Financing Administration, I was able to confirm that, effective 1-1-01, Augmentative/Alternative Communication (AAC) devices that generate speech for people with limited or no vocal ability will be considered "durable medical equipment", and are covered by Medicare. Furthermore, all Medicare beneficiaries who are evaluated by a speech therapist and physician, by whom are determined to need an AAC device, are eligible to receive one.

However, not all AAC devices will be covered. At this point, the policy only covers "dedicated devices", and excludes "computer-based" (multi-purpose) devices. Efforts are being made towards getting this coverage limitation eliminated, as there are many PALS out there whose needs would be most appropriately met by a multi-purpose device.

To the best of my knowledge, Medicare reimburses 80% of the cost of the covered device with the Medicare beneficiary being responsible for 20%. This poses a dilemma in some instances, as the beneficiary is required to pay for the entire amount up front and wait for Medicare to reimburse. Financially, for some this is not possible. Suppliers of medical services and devices who work with Medicare beneficiaries recognize this dilemma, and developed a response, called "accepting assignment." When "assignment" is accepted, the suppliers will require the payment of only a small percentage of the purchase price from the beneficiary, and the suppliers will allow Medicare to pay them the remainder of the item's cost. This procedure substitutes for requiring the beneficiary to pay the full purchase price of the device, and then having the beneficiary wait for Medicare to provide reimbursement. Under this procedure, the beneficiary "assigns" his or her right to Medicare reimbursement to the supplier. Not all devices cost the same, so the amount that the PALS is responsible for paying varies case by case, as each device falls under different Medicare codes.

There is a great deal more information delineated in this policy. For more detailed information on this policy change, please contact 1-800- Medicare or refer to the following website: www.medicare.gov. You may also contact Lew Golinker, Director of Assistive Technology Center in Ithaca, NY at: 607-277-7286, or by e-mail at: lgolinker@aol.com. It is hopeful that other health insurance providers will follow suit with this new Medicare policy. I look forward to hearing from any PALS interested in more AAC information (lindamadole@home.com).



## PATIENT SERVICES PERSPECTIVE

**BY LISA WEINER, PH.D, DIRECTOR OF PATIENT SERVICES—**Over the past four years I have had the pleasure of working with ALS patients and their families. Although, it has been difficult for me to walk the turbulent path from diagnosis to end of life decisions with some of the families who have been part of the Los Angeles Chapter. During 2000 however, I have bared witness to a remarkable new approach to dealing with this disease- Positive Mental Attitude.

**Dr. Lisa Weiner, Patient Services Director of the LA Chapter, speaks about "Living With ALS, Approaches to Coping."**

For some ALS patients, the quest to search for answers has been suppressed by the desire to enjoy what they have TODAY! While more and more ALS patients and family members are taking on this new positive attitude, there are three in particular I would like to mention. They are Morrie Schwartz, Steven Shackel and our very own William Dresher.

As most of you know, Morrie Schwartz was a retired professor with ALS who continued to teach his students the meaning of life until the last of his days. His story, as told in the best selling book and more recently on TV, Tuesdays with Morrie takes us through a wonderful journey in which a man decides to make the most of his time left on this earth. He chose to share his wisdom and positive mental attitude with those around him. What kind of effect do you think his mental attitude had on his ability to continue on after his diagnosis? Without this positive perspective, do you think Morrie would have been able to get out of bed after those moments of depression he experienced in the mornings? I often hear, "Well, Morrie was an unusual man. Nobody is really like that." Well, this article is aimed at proving those skeptics wrong.

Steven Shakel is an MND patient (MND is the term used in Australia for ALS) who presented a speech at a MND/ALS conference last month. He believes that ALS patients should "take some of the burden of directing the outcomes of certain things upon ourselves, especially our personal health and well-being." He accomplished this by utilizing anti oxidants and other natural herbs. He found that utilizing these supplements helped him tremendously is in his ability to walk without aides. Was it the herbs or his state of mind that created this improvement?

He stated in his speech that the answer to this question is unimportant. If the herb solely acted as a placebo, it worked for him. "The body responds in incredible ways to the belief that healing is both possible and imminent...The one ingredient that is most overlooked, or at least grossly underestimated, is the effect of a patients mental attitude on the process of both healing and maintaining good health."

As the disease of ALS progresses, choices become few and far between. The disease dictates if and how persons with ALS can communicate or use their muscles. One of the choices that Persons with ALS do hold onto however is the choice of how he/she will sustain the will to live.

William Dresher was an ALS patient and member of the Los Angeles Chapter. I had the pleasure of meeting Mr. Dresher during a home visit. Much to my surprise, I found that I could not release the smile from my face during our entire 2-hour visit. Mr. Dresher has an uncanny way of finding humor in the obstacles he faces during the progression of his disease. He is creative in his problem solving, and fully enjoys his time with his friends and family. My experiences with "Bill," however, were not all smiles. I found myself in tears over an e-mail I received from him.

He sent me an animated story about a young boy who approaches an old man on a park bench and asks, "Isn't it a beautiful day?" The old man looks up in the sky at the rain clouds and looks awkwardly at the boy. The young child walks away briefly, only to return to bring the old man a dying flower. The young boy exclaims, "Isn't this a beautiful flower?"

Bewildered at his choice of a dead flower to attribute such beauty, the old man shuns the young boy. Upon taking another look at the boy however, the old man realizes that the child is blind.

At the bottom of this story is a blurb about how people tend to become enveloped by their own tragedies, and fail to look at the beauty around us. While the story itself was moving, even more so was that an ALS patient in the crux of his disease, can put his own tragedies in perspective, and go on to enjoy each day and the rewarding experiences those days provide.

The power of a positive attitude is sorely understated. Why not empower yourself in the year 2001?

## A SPECIAL CASE

**BY LOTHAR DELGADO, MA, ALSA CASE MANAGER—**When Jim*, a 40-year-old father of three young children, noticed a drag in his left leg after a long bike ride with his family he thought little of it. Perhaps it was muscle strain. His active work life and routine exercise regime certainly provided opportunities for some unnoticed injury. Within a month the drag had worsened and his wife noticed changes in his speech. His internist recommended neurological tests and the neurologist delivered a diagnosis of ALS. Jim's thoughts flashed to an aunt who succumbed to ALS 15 years ago. He thought of his cousins and how having a parent with a life threatening illness had affected them.

Jim and his wife ran the gamut of emotions in the first months after diagnosis. Fear, anger, frustration and depression overwhelmed this couple as they struggled to keep the bad news from the children, aged 6,8 and 13. After attending several ALS support groups and reading literature on how to talk to children about ALS they decided that that they were ready to bring the children into the circle of a family living with a life threatening illness.

It takes courage to live each day as the best one we have. Jim's children, each in their own way, knew that the balance of life had been somehow shaken. Their parent's decision to include them, to the level they could understand, in the battle gave them strength and hope. Several family rituals helped them to cope with the changes. Regular family "check-ins" gave them all a safe place and time to talk about dreams and fears, to plan for a different future. The family created a joint project of a memory book. Finding pictures stored in boxes of fun vacations and important family events, they gathered in a circle around the kitchen table to paste them into an album and remember the good times these pictures had captured.

Jim's 8 year old daughter and 13 year old son began to attend a support group for children who face the life-threatening illness or death of a loved one. They looked forward to attending each week where, with other children and the help of a therapist, they explored difficult feelings. Through art, games and talk they found comfort and hope to process their losses.

Acceptance is an inner process. It takes a lot of hard work and so much energy to deal with change. You can help your children to navigate these dark waters by recognizing that this is a tough time for them and by acknowledging your own feelings to them. Statements such as: "I feel sad (or frustrated …lonely …angry) can go a long way to normalize the similar feelings they have, but don't verbalize as they attempt to recreate the lost family balance.

In facing the reality of living with ALS as a family, Jim and his wife helped their children think about issues relating to spirituality, encouraged their participation in sports and fun activities, enjoyed nature together and connected them with other social groups. Even though, as parents, they often felt overwhelmed, they found other caring adults to spend time with them as a way of restoring some of the security and normalcy to life. Perhaps the most meaningful gift they gave to their children were the smiles, the hugs and the sincerely meant "You're a great kid!" spoken often by parents who loved them.

**The name of the PALS has been changed for privacy purposes.*

## FROM THE VENTURA SUPPORT GROUP...

**BY JOYCE LAUTERBACK, SUPPORT GROUP LEADER—**We brought the year 2000 to a close with a wonderful presentation by Tom Hollingstein representing Adaptive Driving Systems. Tom has been a wheelchair user for 15 years because of a spinal cord injury. He showed us a minivan with a fold-out ramp adapted to lock in a wheelchair into the passenger side of the vehicle. So many questions were answered from obtaining a van to the myriad of ways it can be adapted to accommodate PALS. I am sure we will have Tom back before the end of this year to update us on any new developments in driving systems. In addition to all of that valuable information, he also provided us with the opportunity to meet his assistance dog trained by Canine Support Team, Inc. and learn more about these wonderful service animals.

In January, Megan Nugent MFT, spoke to the group about stress management and techniques to reduce it for PALS and their caregivers. Ferne Hayes PT, Patient Services Liaison and Chapter Equipment Loan Pool Director, will speak to our group at our February meeting, so come prepared with questions about mobility, transfers and equipment concerns. March brings Ann Gessert MFT, to teach us the intricacies of family interactions and the buttons that get pushed between PALS and their

Please see *Ventura Support Group* on page 8

Simple Wishes, from page 1

pilot friends of his had designed a harness to get him in the plane. They lifted him up into the air and backed the plane up so that it was directly under him and then they lowered him into the pilot's seat of the open cockpit plane. As uncomfortable as the whole process must have been for him, that smile never left his face.


**The Petrini family prepares for flight**

So, there he sat, in the cockpit of the plane, complete with a leather aviator cap on his head (unfortunately, we weren't able to find a scarf to complete the image), waiting for take-off. I don't think that I can even put into words how great it was to watch my dad as he sat there. This was a dream come true for him and it was written all over his face. I'll never forget his expression when the engine of the plane started and they began to make their way to the runway. He looked at me as if to say. "That was the noise I was talking about."

As the yellow and red biplane prepared for take-off, we were blessed with another surprise; three of the people who helped get my dad safely in the plane, including Kendel Hanson, were pilots. They graciously offered to take those of us who were watching into the sky so we could watch Dad's adventure. Ten minutes later, three planes, carrying eight family members and friends lifted off into the blue sky.

Once we were in the air it didn't take long to spot the vintage WW II plane doing spins and dives against a backdrop of ocean and clear skies. It was so exciting to watch. Eventually all four planes came together in a formation that allowed us to see Dad close up and to see that he was still wearing that smile. He even looked over and waved at us.

I can't even tell you how much that day meant to everyone who was involved, especially my dad. Even those people who had never met our family before were touched by the events that unfolded on that beautiful Saturday afternoon. When my dad's plane taxied back into the hanger, he was greeted with cheers and applause, laughter and tears. I know that, once again, he went to sleep with a smile on his face.

My dad has gone into the depths of his heart and found a new appreciation for life and passion for living that has become highly contagious to all who come in contact with him. Anyone, who has the privilege to spend even a few moments with him, will undoubtedly walk a way with a smile on his face and a light in his eyes. That day my dad fulfilled a dream of a lifetime and painted a memory that will forever be in our hearts.

Ventura Support Group, from page 7

families, caregivers and friends.

For the rest of the year, speakers will include Diana Guth, Home Respiratory Care, to address breathing and sleeping solutions and a speech therapist who will discuss speech, swallowing and eating, and Linda Madole, Director of Augmentative Communication, who will discuss available equipment.

In the Ventura Support Group, we have a mixed population: PALS who are newly diagnosed, PALS who have had ALS for 2 to 5 years and are still mobile, family members who attend with PALS and family members of PALS who cannot attend. We have PALS who come from as far away as Bakersfield and San Luis Obispo to Simi Valley and Westlake Village. The best part is that every month, someone shares valuable information found through researching the web, following legislation, experience with a simple device that makes life a little easier, and advice gained from their own trials and tribulations. This is always generously and lovingly shared with each other. JOIN US!

## A POSITIVE NOTE

**BY ANN VERPLANCK, CASE MANAGER—**In the past, I have written about people I am working with and things that I have been able to help them with as their Case Manager. This time, I thought I would depart from that tradition and write about something that I find very useful and helpful in my life—trying to have a positive outlook and use positive energy in my life.

Here is a little tip that some of you probably know about, and it may be new to others. One way to accentuate our positive outlook on life is to use the technique of LIGHT. Yes, you read correctly, LIGHT. Light is one of the most positive energy forces we have available to us. When I speak of light, I mean any kind of natural light. It could be sunlight, firelight, candlelight, moonlight or any other kind of natural light you can think of.

Here is how it works. As you are holding a positive thought about someone or something or doing a creative visualization, surround that thought in any form of natural light. As you are working to heal yourself and stay healthy, feel the light surround you. If you choose sunlight, feel it beaming down upon you, coming into the top of your head and moving down to the tips of your toes. Feel it in every cell in your body.

Another way to use light is with conflicts you may be having with other people. Perhaps you've had an argument with someone. Perhaps you are holding onto an old grievance or having trouble forgiving someone for something real or perceived that they have done to you. When that happens, you can heal the grievance or anger by closing your eyes, and imagining the other person about 6 feet in front of you. Next, imagine bringing that natural light down through your head and into your heart. Then, imagine sending or transferring the light from your heart to the other person's heart. Keep sending the light until you can feel a shift in the anger or negative emotion inside of you. All you need to feel is a slight change in your feeling state and you'll know that you've been successful in using the light in a positive way.

Then, watch what happens. I guarantee that something positive will. I've used this technique in many areas of my life. Here's a silly, small example. When I am in a long line at the bank, I draw the light to me and then send it to each person in front of me. Within minutes the line will begin to move. Sometimes another teller will open a window, or there are no new tellers, but the line just inexplicably begins to move faster.

By feeling the light within ourselves and then sharing that light with others, our positive thinking and outlook on life will improve greatly. This technique may be a little too far out for some of you. If so, please ignore it and move onto the next article in the newsletter. But, if you have not tried working with LIGHT and you find yourself in a particularly challenging situation, you might give it a try. If you do try this technique and it works for you, I would be interested in hearing the results if you feel like sharing with me. Thanks for being open to a different perspective on how to increase your already positive outlook on life. Ann can be reached through the Chapter office (818) 865-8067.

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, California
91376-0565
(818) 865-8067
fax (818) 865-8066

## 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.

February 17 — Katie Gundersen, Small Assistive Devices for Easier Eating and Dressing

March 17 — George Varjas, Navigating our benefits (Medicare, medical social security, disability, private insurance)

**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

February 24 — Ferne Hayes PT, mobility, transfers and equipment

March 24 — Anne Gessert MFT, family dynamics

**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.

February 10 — Nutrition and ALS

March 10 — Accessing Loan Pool Equipment

**Temas y Fechas para el grupo de apoyo**

10 de febrero, 2001 — Nutricion y ALS

10 de marzo, 2001 — Como obtener equipo medico prestado

**Westside**

**Note:** New Location and Date:
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

February 3 — Introduction (getting to know each other) and determining needs and goals

March 3 — Dr. Graves, ALS 101 and updates question and answer

## NEWS FROM THE MONOLINGUAL SUPPORT GROUP

As of January 2001, the Spanish speaking support group will meet at a new location. We are now meeting on the second Saturday of the month from 3:00 PM to 4:30 PM at the City Terrace Library. Everyone is welcome to attend.

Please contact Martha Mowatt at 562-997-3150 or leave a message at 562-889-9452, for additional information or to obtain directions.

## NOTICIAS DE PARTE DEL GRUPO DE APOYO DE HABLA HISPANA

Empesando enero, 2001, el grupo de apoyo se reunira en la bliblioteca de City Terrace el segundo sabado del mes de 3:00 pm a 4:30 pm. Por favor comuniquese con Martha Mowatt al 562-997-3150, o deje mensaje al 562-889-9452, para obtener informacion adicional. Todos estan invitados.

## FROM THE ADVOCACY CHAIR

**BY DR. JEANNE MOLLER**

**FONTANA—**There is hope. It is amazing how in a short period of time the ALS community has accomplished so much. Our most recent accolade is the passing of the bill HR353. What does this mean to PALS*? The Social Security Disability waiting period is a mandatory twenty four months from the time one applies for Medicare Benefits until such benefits are received. This applies to those who are unable to work, due to a number of reasons, and are less than 65 years old. For members of the ALS community, this is devastating. One can only begin to imagine the struggle many PALS and their families endure; not only are they faced with a debilitating terminal disease, but many are burdened by financial responsibilities– many become financially ruined.

**We are now in a time of positive change! Through the efforts of so many wonderful people, people dedicated to making a difference, the two-year Social Security Disability waiting period has been waived for PALS.**

To date, the best that we can do for PALS is to improve their quality of life. Many times this is accomplished through medical equipment, such as computer assisted communication devices, wheel chairs and their accessories, home evaluation and assistive technology, and one cannot place a monetary value on the endless hours of emotional support provided by The Greater Los Angeles Chapter Patient Services staff.

We are now in a time of positive change! Through the efforts of so many wonderful people, people dedicated to making a difference, the two-year Social Security Disability waiting period has been waived for PALS. Although we will not fully know the specifics of the legislation that has recently been passed for several months, we are hopeful that our PALS will benefit greatly.

While there are many to thank for this success, I am reminded of my first trip to Washington, D.C. to attend ALSA National Advocacy Day last May. The Senate Labor, Health and Human Services and Education Appropriations Subcommittee, chaired by Arlen Spector, heard a number of moving, astute and clear reasons why this committee should support our plea to waive the two-years waiting period, provide medical coverage for all FDA-approved drugs and to increase NIH resources directed towards ALS research. The room held approximately 300 people and there was not a dry eye in the house. After the completion of the hearing, ALSA representatives spent the day lobbying members of the Senators and House of Representatives. It was a flurry of activity, an especially exciting and challenging day.

Nine months later, I found myself standing in front of a news reporter covering a press conference for Congresswoman Lois Capps, who is credited with "shepherding" HR353 to victory. As the daughter of a PALS, and as a physician, I was proud to represent The Greater Los Angeles Chapter and The ALS Association at that historic moment as I shared feelings of relief and hope on the part of our community.

**PALS – person with ALS*

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*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 October, 2000 to January, 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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