

EXECUTIVE DIRECTOR'S REPORT By Ray Corvan



Ray Corvan

As I am sure you have heard, over and over again, this has been a very bad year for raising money. The stock market is down, companies are laying people off, the threat of terrorism is up and things just don't look as good this year as they did last year. All of this may be true, donations are down, foundation grants are down and people seem to not have as much disposable income as they had in the past.

But I will tell you something. Special Events are up and very profitable. We had our first ever Sporting Clays Event

this year and raised enough money to cover operating expenses for almost a month. One of our volunteers put on a "Dance of Life" for us, and another volunteer hosted a dinner at Moomba Restaurant in Hollywood, which raised much needed capital for us. Just last month we finished our annual golf tournament and it more than doubled what we raised last year. We netted over \$75,000 from that one event. Now we are looking down the barrel of our annual Walk to D'Feet ALS™. Our goal this year is to gross over \$200,000. We already have over 100 team captains and we are hoping for over 1,000 walkers.

Knowing that the economy was down and that money was tight, we decided earlier this year to place a special emphasis on Special Events and as you can see our preplanning has paid off.

While I have the floor, I would like to mention an event that was brought to me last month. A Poker Tournament. To be held at the Bicycle Club Bell Gardens. This event will take

place if there is enough interest from our supporters. If you have an idea for special events please contact me at the chapter. I promise to listen to all ideas.

Having said all this, I still need to tell you that we continue to need your help. You still have time to join the Walk to D'Feet ALS, either as a walker, or a contributor. Our PALS (Persons with ALS) deserve our support in their courageous battle with this debilitating disease.



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OUR HOLE IN ONE

by Cecile Falk Balsler, President

On Monday, July 22nd, we had our second annual golf tournament at the lovely North Ranch Country Club. This event was a huge success in many ways. The 2002 Authentic Swing Charity Golf Tournament committee, headed by Board member George Powlick and Director of Special Events, Giovanna D'Angelo, worked hard and effectively. Our gratitude and appreciation goes to the committee and all of our participants. Everyone enjoyed the day on the course and the chapter is benefiting financially from this successful event. Our net receipts doubled those received last year.

You, our members, participants, and volunteers, are our "Hole in One". We thank you for working and playing with us. Our events are a crucial part of our fund raising process. Every dollar we receive from these activities enhances



Cecile Falk Balsler

the services we provide to our ALS community. During the coming year we are going to expand our events and we look to you to continue to come out and play with us. Those of you who have ideas about possible events, please contact our office. We will let you know of future events as they develop. We expect to see our golfers at our Walk to D'Feet ALS on Saturday, October 5th. Thank you again. Enjoy

CART'S Corner

by Barb Phillips, OT

The Las Floristas Center for Applied Rehabilitation Technology (CART) at Rancho Los Amigos National Rehabilitation Center in Downey, has been working in collaboration with the Los Angeles Chapter of the ALS Association for over 5 years now. We provide assistive technology evaluations, recommendations, training, and follow up services to children and adults with physical disabilities. The staff at CART consists of Speech, Occupational, and Physical therapists as well as assistive technology "experts", including a Rehabilitation Engineer and Assistive Technology Specialist.

There are four main assistive technology areas that we address: 1) Augmentative Communication (AAC) interventions are for individuals with speech impairments that range from low volume or slurred speech to no speech at all, 2) Seating, Positioning and Mobility, 3) Computer Access which includes software and hardware adaptations, 4) Electronic Aids to Daily Living (EADLs) are fancy remote controls that allow independent control of electronic devices in the environment such as telephones, lights, televisions, stereo, and other electronic systems.

There are wide ranges of assistive technology available. Some people will benefit from "low tech" solutions, while others require higher end solutions. In any case, services are available to any individual with any type of physical limitation. It is difficult to anticipate future limitations, but educational

Volunteer Services Experiences Dynamic Growth!

by Molly Rockey, Director of Volunteer Service

In 1999 a group of brave hearts combined their creativity, passion and dedication and went to work volunteering for The ALS Association's Greater Los Angeles Chapter. That year the organization was finding its wings and exploring the path of community service as a way to grow. The invitation to become a part of a team that makes a difference was sent out through newsletters, appeals to friends, and public speaking opportunities. We started growing - expanding the number of people who came to help from just 27 in 1999 to 175 in 2000, and 575 volunteers in 2001. An increase of over 2000% in just two years!

Many of our "helpers" come through

The Augmentative Alternative Communication Department

by Linda Madole, AAC Director

In the past couple of months, I've encountered a number of PALS who weren't certain about where to turn for their Augmentative alternative communication (AAC) needs. Therefore, I'm going to address that question in this month's newsletter article.

I consider this program to serve not only as a loan library for PALS, but also an augmentative communication assistance program. I can help PALS get AAC—from the evaluation to the initial set-up and training with the equipment.

In order to access our AAC loan pool, you must first obtain an augmentative communication evaluation. I can help you determine which kind of evaluation is appropriate for you and how to expedite it. If, after the evaluation has been completed, AAC equipment is needed, I can assist you with pursuing insurance for funding. In some cases, insurance will not fund AAC equipment (speech generating devices). I may be able to provide alternative equipment when the recommended equipment is not available. ALSA GLAC can also loan to PALS, in the interim, while waiting for insurance to fund the recommended equipment. ALSA GLAC is happy to loan the appropriate equipment, as long as it is available in the inventory.

If you have any questions, or need assistance getting started with AAC, please do not hesitate to call me, Linda Madole, AAC Director, at: 310-514-8228; or e-mail at: lindamadole@cox.net.

opportunities can be made available. Since all the staff providing evaluations are therapists, a referral must be made from a primary care physician. Most medical insurances pay for the evaluation and some pay for some of the technologies. There is loaner equipment available for AAC and EADL programs through the GLAC of the ALS Association.

For additional information about CART, call (562) 401-6800 or visit our

website at: www.rancho.org/cart. For information about the EADL and AAC Loan Programs, contact Linda Madole at (310) 514-8228 or Lindamadole@coxnet.com.

Barb Phillips is an Occupational Therapist working at CART, in Downey, CA.

for us at major events, educational programs and fundraisers, while others work silently behind the scenes making home visits, doing research, facilitating letter writing campaigns, speaking at support groups, participating in strategic planning sessions, and overseeing various activities. Training programs are now in place to ensure that the "Pals for PALS" (PALS is a Person with ALS) program has visiting volunteers oriented to the unique challenges of people touched by ALS. The Equipment Loan Pool is reaching out to Southern California Rotary Clubs to create "relay teams" to move durable medical equipment over our three large counties. Simple Wishes, under the care

of Barb Phillips at the Center for Applied Rehabilitation Technology (CART), has completed 30 wishes for PALS. College students come to us for internships and service learning projects.

As we grow in numbers, we are learning together how to best share our talents and make our own unique contributions. Support for the Volunteer Services department comes from foundations and individuals who strongly believe in our work. They include: The Lon V. Smith Foundation, Max Factor Family Foundation, and Vernon Kotula. Special thanks to our volunteers and funders. The work of The ALS Association is made possible by YOU!

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 June 1, 2002, to August 31, 2002. Through these donations the Chapter provides a way to remember and pay tribute to those who struggled valiantly in battling ALS. In addition, because of your care and support, we are able to continue providing valuable patient services to individuals with ALS and their families, and to support needed research.

If a family member or friend has died of ALS and you wish to honor their memory, you may, in lieu of flowers, request donations to the Chapter. Please designate in the death notice that donations should be made to The ALS Association, Greater Los Angeles Chapter, PO Box 565, Agoura Hills, CA 91376-0565. You may request a supply of tribute envelopes to have on hand at the funeral home by calling (818)865-8067..

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Volume 3

FOCUS 2002 / Building Bridges to Our Resources

OUR MISSION

To be the central source in the Greater Los Angeles area for services and education for ALS patients, families and caregivers. ALS is also known as "Lou Gehrig's Disease"

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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.

Walk to D'Feet ALS™ Kickoff Party

Giovanna D'Angelo, Dan Borchers, Molly Rockey



Walk to D'Feet Committee Members Peter Pierce, Cathy Ostiller, Dan Borchers, Liz Bluestein Robert Golshan



Case Managers - Pedro Loza & Janet Yamanishi



Joan San Fillipo, Giovanna D'Angelo and Rosalie Meyer prepeare to welcome guests.

The E-Team-Walking to D'Feet ALS

By Ellen Burke

It's been a year since the Greater Los Angeles Chapter of The ALS Association held its first fund raising walk-a-thon. I was among those who participated. It was an eye opener to see the bustling activity of teams of PALS (Persons with ALS), families, and friends who were there to raise community awareness of this devastating disease and money for both patient services and a cure. I was happy to see the cheerful mood that prevailed. Colorful banners honored and remembered loved ones. Wheelchairs, strollers, and pets decorated with streamers and balloons made everyone smile, while tee shirts with beautiful photos and quotes tugged at our heart strings and reminded us over and over again why we were walking. Among those who attended were Chapter friends, Carl and Barbara Frova. I was delighted to say "hello" and meet them personally. Carl's opening words of encouragement and hope set the tone for the day. His challenge to each of us affected by ALS to do those things that we enjoy, and can still do, has stayed with me all these months.

I was diagnosed with ALS in December of 2000. Though my mobility has decreased, my spirit remains charged and keeps running full tilt with the support of my sons and ever-present dear friends. I am taking this spirit



Ellen and the E-Team

into a letter writing campaign and asking everyone I know to make a donation for our cause. I am taking this spirit to the Walk to D'Feet ALS in Santa Monica on Saturday, October the 5th. I invite everyone to come out and join me. I promise it will be a day of fun, whether you choose to complete the 3 mile wheelchair accessible course, or simply sit under the trees in the park and enjoy the colorful festivities. We have a lofty goal this year - to raise \$200,000 for local patient services and to fund research for a cure. Together we can do it! Sign up to walk by contacting the Chapter office at alsaglac@aol.com or (818) 865-8067, or register online at www.walktodfeet.kintera.org/losangelesca. I look forward to seeing you on October 5th with all your friends and family.

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