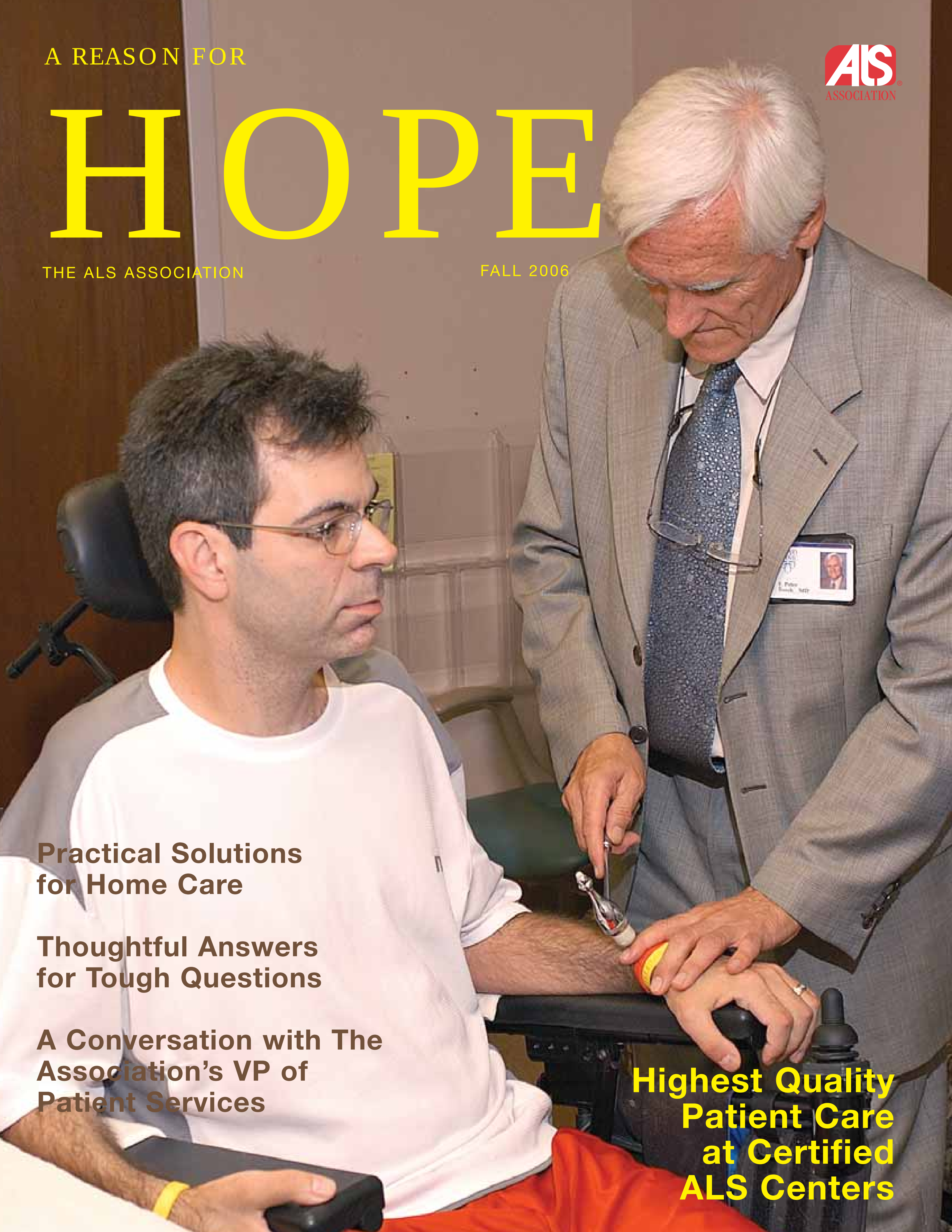

A REASON FOR

HOPE

THE ALS ASSOCIATION

FALL 2006

Practical Solutions for Home Care

Thoughtful Answers for Tough Questions

A Conversation with The Association's VP of Patient Services

Highest Quality Patient Care at Certified ALS Centers

A REASON FOR

HOPE

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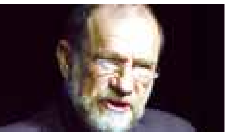

ABOUT THIS ISSUE… *A Reason for HOPE* strives to inform our readers about advances in research, patient services and advocacy efforts, as well as features articles about people in the ALS community. This issue focuses on the services provided to people and families living with Lou Gehrig's disease and the efforts of The Association to improve living with ALS.

One of the major beams supporting the foundation of The ALS Association's patient services is the growing network of Certified Centers of Excellence(SM) for care of ALS patients. Readers will learn about the multidisciplinary approach that provides the "gold standard" for care and the confidence that the care is being managed to provide the maximum benefit to the people with the disease.

HOPE spoke with Sharon Matland, The Association's vice president of patient services, about the care and services available and some of the exciting new programs on the horizon. In addition, Matland describes the unique relationship between chapters and ALS centers and clinics that provide a nationwide network of care and support to patients, families and caregivers unmatched anywhere else in the world, with such initiatives as the "Care Connection," a pilot program to help families organize support teams to share the responsibility of patient care.

In the article "Tough Questions, Real Answers," The Association's National Laureate Noah benShea takes a sober and heartfelt look at some difficult and important questions asked by people with ALS and their families. This is compelling reading for anyone facing life at the crossroads.

HOPE magazine is designed to be informative and useful. As always, we invite your comments and suggestions regarding the publication. HOPE is available on The Association's web site, http://www.alsa.org/resources/magazine.cfm and through e-mail distribution. To subscribe, visit http://www.alsanews.org/mailman/listinfo/hope and follow the instructions.

Greg Cash

Greg Cash
Editor & Director,
Communications

On the cover: Pictured are Douglas Charais, who has been living with ALS for more than three years, and E. Peter Bosch, M.D., director of the ALS Clinic at Mayo Clinic in Scottsdale, Ariz., a Certified Center of The ALS Association. The photo was provided by Mary Knopp of Randall Photography.

THE ALS ASSOCIATION FALL 2006

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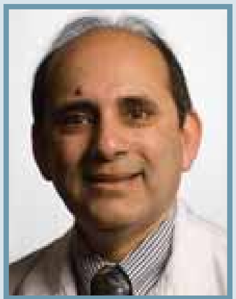
The ALS Association Centers

Provide Quality Care and Peace of Mind

By Gary Wosk, Staff Writer

Edward Newell, diagnosed with ALS in 1999, felt uneasy knowing his occupational therapist had to constantly call the school she graduated from for advice on how to treat him. Granted, he admits, everyone has to learn sometime, but quickly adds, "not on me."



Rup Tandan, M.D.

His outlook on care brightened when he began receiving care at the University of Vermont-Fletcher Allen Health Care ALSA Clinic, where he is seen by a multidisciplinary team of ALS specialists.

"The fact that I see them continually," said 71-year-old Newell, "I have more confidence in them, and I have a better feeling knowing that they are interested in taking care of me. The Center is up on the latest advances."

Newell and thousands of people living with ALS are receiving the highest quality of care from The ALS Association's Centers℠, also referred to as Centers of Excellence, which continue to sprout across the nation. In 2004, there were only 19; today there are 28.

"The Center is very positive, very well set up," Newell said.

The Association's gold standard of care in the management of ALS was established in 1989 when The Association certified its first Center, the Forbes Norris ALS Research Center in San Francisco.

> "I have a better feeling knowing that they are interested in taking care of me."

"It is reassuring to me to see that patients can utilize these special services available to them," said Rup Tandan, M.D., medical director of the University of Vermont-Fletcher Allen Health Care ALSA Clinic. "Often, making a small but visible difference to the health and well-being of patients and family members is very encouraging, and a big impetus for the team to continue service to this patient population.

The Centers and The Association's national network of chapters have been working closely together to provide empathetic, all-encompassing care. "The close working relationship and partnership with The Association's Northern New England Chapter facilitates this care delivery," Tandan continued.

Several studies conducted in Europe within the last 10 years confirm that ALS patients who receive a wide range of care under one roof have a better chance of living longer and having an improved mental outlook.

"A primary goal for people with ALS who attend the Centers is to have a positive impact on their mental outlook and improve their quality of life," said Sharon Matland, patient services vice president for The Association. "They see an entire team of people who are focusing on them, and they know they can call on this team of people at anytime. They are not alone. This is a real community."

During their visits to the Centers, patients usually are examined by a neurologist, registered nurse/clinic coordinator, physical, occupational and respiratory therapists, dietitian, speech and language pathologist, and a social worker. The entire visit lasts an average of two to four hours.

"It saves them time, it saves them energy and it saves them stress," said Jennifer Brand, patient services director for The Association. "It saves them the inconvenience of being referred at varying locations and on multiple days."

The multidisciplinary team at Banner Good Samaritan Regional Medical Center ALS Clinic in Phoenix, Ariz., includes (standing, left to right) Kathy Crowley, social worker; Kim Hughes, Arizona Chapter patient services coordinator; Ron Hankins, speech pathologist; Jo Tanzer, Arizona Chapter patient services director; John Bargas, physical therapist; Diane Johnson, occupational therapist; Jackie Groscost, administrative assistant; Dee Gnagbe, R.N.; Dave King, respiratory therapist; (seated left to right) Melissa Ponce, R.N.; Todd Levine, M.D. and medical director; Kris Irizarry, R.N., M.S.N., C.R.R.N., clinical director.

No questions go unanswered at the Centers. Patients leave with a greater sense of how the teams will improve their quality of life and what they will experience.

"People with ALS want us to anticipate what their needs are going to be," Matland said. "We need to provide information so that they can make informed decisions about their care and available treatments. This is a major component in how patient services and Centers can support people with ALS."

Life With ALS
Tough Questions
Real Answers

By Noah benShea

Hello, my name is Noah benShea. I am the National Laureate for The ALS Association. In 1990, I lost my father to ALS. To this day I still have more anger than peace, more questions than answers.

Noah benShea

Nevertheless, over time I have learned a few things about coping with ALS even though most of the education came from feeling beat up, watching my mother get pummeled by events, and simply witnessing my dad's daily honored courage in the face of fear and fate. The few words you are about to read aren't intended to be the final word on the questions at hand but are the best I can do in trying to offer you a few words, when the truth is that words generally fail in life when you need them most. And it is with the humility of knowing this that I invite you to read on because I believe my heart is in the right place – right next to you in the corner where you feel cornered. At least that is where I have attempted to park my best intentions.

> "From being honest with ourselves, we can begin to find our way with others."

How do I tell my family, particularly my children, that I've got ALS?

It always seems to me that the toughest place to begin with any of the tough issues in life is with ourselves. So perhaps before we get around to trying to tell anyone else what has got to be devastating news, the place to begin is by having a conversation with ourselves. Before we think of breaking the news to anyone else, I think it serves us to make sure we are being straight with ourselves. The truth starts at home.

This doesn't mean we don't say anything until we are past anger, denial or the like, but it does mean we are being straight with ourselves about what we're feeling facing this monster.

From being honest with ourselves, we can begin to find our way with others. If we can be self-loving in the face of the facts, then we have a much better chance of being other-loving when we share the facts with others.

And while we can't presume how others will take the news you share with them, neither can we presume where the news is going to take you –and living with this uncertainty is certainly the first fact that needs a face to face. Suddenly, for both patient and family, what we have to face is that all the previous presumptions we had about life were just that, and for most of us this is the hard news of the human condition as much as the diagnosis.

In no small way, facing ALS forces us to face what it means to be a vulnerable human being. And the usual tactical avoidances of having plans, being busy or being young are all washed away leaving us nose to nose with the dragon whether that dragon is ALS or simply facing the fact we're all growing older and soon will get yanked from the stage of our day to day dramas, comedies and triumphs.

Still, at the end of the day, what do you say to your family and your children? Tell them that you love them. And you need their love. And when things get tough for them it will be tougher yet for you. And what will hold it all together is the knowledge that though we will be pulled apart, this experience can also pull us together.

The doctors are telling us that my dad is failing really fast. What is the best thing I can do for him? I need answers.

ALS answers to no one. And while I have been down this road a ways, the journey only convinced me that I do not have answers. I do have thoughts.

I believe there is no more important message for any of us to share with another than to remind them they are loved now, and forever. And that is the heart of the matter, no matter what any of us are dealing with. And that is the best deal we can make with another. And the best deal we can make with ourselves.

"Reality is only a memory ahead of its time."

Against your father's fears, and your fears, wage love. Wage love for him. Love in the moment. Love with ferocious tenderness. Love for the moments you yet have, no matter how you feel the moments have been robbed of what they once were, because all moments are only what they are becoming before they are gone. For all of us, reality is only a memory ahead of its time.

Remind him that he has not done anything wrong. And remind yourself that you have not done anything wrong. ALS is not a punishment. It is not a defeat. It is a fact, and a fate, and fate plays in all of our lives. It simply is. And like with each of us, it is what we make of it. And when we feel like we are failing of courage, this is our shared humanity, and our shared courage of day to day living – for all of us.

Love the moments, and your father, and yourself in this moment. Embrace this time even as you would like to be embraced and told with heavenly certainty that all will be okay. Let your father know that his love is what has made your life great and to think otherwise would be as great a mistake as it would be to confuse fear with failure.

Wrap your father in prayers. Let him know that these are angels' wings lent to you for just such a purpose, lent to protect him with your spirit, and the greater spirit beyond all of us, above all of us, within all of us.

Why is this happening to me?

The short answer is, no one knows. And while our books of wisdom don't give us answers, they do tell us of people who have to live without answers and the heroism of bedding down with questions that don't let you sleep.

Across history, too many of us have felt that we have been handed a bad hand. And our heart can historically ache for them without diminishing the pain they experienced.

I'm not sure the lawn knows why it gets mowed, or the wind knows why it gets shoved around, or the rain knows why it falls in gutters. And though none of this will give any of us living under tough circumstances any peace of mind, I do know that things don't have to be good for us to be great.

For your great anguish, I am sorry that this is happening to you. I am also sorry that it happened to my dad. And I'm surely sorry that in some way it also happened to my mother who, when my father was in the hospital, found herself living in the halls of the hospital. But now that my dad is gone 16 years, I don't think of him framed by ALS but by the giant inside the man he was. And in my prayers when I visualize him, what I cherish about him has nothing to do with ALS and everything to do with him. So while this is happening to you, "you" are much more than what is happening to you. You are more than what you are feeling. You are the feelings you have touched in others. And this flame will not go out. This "you" will spark and ignite souls you will never know, touched by you in ways you never imagined. Imagine that.

"Heroism is not the absence of fears, but how we wrestle with our fears."

How can my family, who are watching what is happening to me, draw not only pain but strength from what I am going through?

Again, the self is always ground zero. If we want others to witness what we are going through – no matter what we are going through in life – not only for its pain but for its ability to pass along strength, then we have to draw strength from the well of our experience.

Is this easy? No way. Can others make it any easier for me? Maybe, but in the end, the pain of isolation, often the most profound pain with ALS, is not, by definition, shared.

So how can others draw strength from our pain? By witnessing in our lives and in their own lives that victory is not in vanquishing what we are combating but in how we choose to fight it, and who we are in the process, and what face we wear to the day to day horror show. In our shared vulnerability is our shared humanity and shared heroism. Heroism is not the absence of fears, but how we wrestle with our fears.

Every one gets their shovel of dirt in life. With ALS however, the dirt is shoveled on you with a bulldozer. In the face of this shared truth, what remains for all of us is how we deal with what's been heaped on us. Dignity is not derived from absence of discomfort in one's life but the dignity we bring to the discomfort. And because with ALS, the discomfort is not simply burdensome but burying, the dignity to be derived and witnessed is also inversely regal.

It's hard to tell how much imprint we have on the lives of others. I am reminded of children who, without mindfulness, in a summer afternoon run through wet cement and leave footprints drying in the sun even as they sit at home later that evening unaware they have left their mark.

How others will witness our struggle can be a source of inspiration even as we only witness our perspiration in getting through the day. Still, none of us should imagine that if our courage stands in the sun that we will not cast a shadow of influence.

I recently received a long note from M. with ALS. I had just woken and had a full day of writing ahead of me that I knew would be challenging. But before beginning my work, I paused, perhaps to avoid my work, to read his note. Toward the end, M. apologized for some of his grammar and explained that he was typing the note with a stick in his mouth tapping out each letter and every five or six words he had to stop and get on the ventilator. And when I read that, I stopped too, stopped hard. Suddenly I was no longer burdened by the prospect of my day's work. I was inspired. M's courage was contagious.

P.S. After I wrote M. back, he replied by telling me how honored he was to get my note. And when I read that, and I thought on how hard he had to work to even write that to me, I cried. I cried to be in the "company" of his heroism, and I believe that in some way it made me a better man.

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To read more real answers to tough questions from Noah benShea, visit http://www.alsa.org/benshea/article.cfm?id=998

Scientist Obsessed
with Unraveling the Mysteries of ALS

By Roberta Friedman, Ph. D., Research Information Coordinator

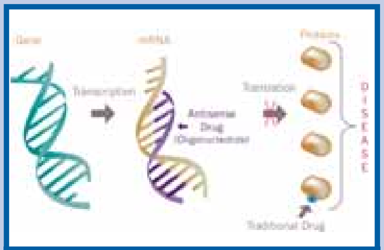
Don Cleveland, Ph.D.

Amyotrophic lateral sclerosis has the compelling power to draw in those with a personal connection to this disease. For Don Cleveland, Ph.D., one of its most recognized experts, the introduction to ALS was by chance a decade ago.

> “Initially, it was scientific curiosity.”

“Initially, it was scientific curiosity” which brought him to the ALS field and to The ALS Association as a scientific advisor and grantee, Cleveland says, “but it’s become its own seduction.”

Cleveland had been working on how the longest cells in nature, the motor neurons, can reach from spine to toe tips and maintain the flow of cellular nutrients up to a meter to the target muscle. His small team was using brand new tools of molecular biology to manipulate the proteins in nerve fibers called neurofilaments, the structural elements that support and supply both neuron and muscle. “We engineered mice to have too many neurofilaments, and they got motor neuron disease. We realized we had just taught ourselves how to make a mouse model that mimics ALS.”



Traditional drugs block proteins that cause disease; however antisense drugs interrupt instructions from the DNA to prevent production of targeted proteins. Image courtesy of Isis Pharmaceuticals, Inc.

Mutation Can Produce ALS

By chance, this finding on neurofilaments was published at the same time as the discovery of the mutation in the enzyme, copper-zinc superoxide dismutase (SOD1), responsible for some inherited cases of ALS. Cleveland realized his lab could now start to focus on how SOD1 causes the disease.

It was also at this time that a postdoctoral fellow came to work on the neurofilament project, Lucie Bruijn, Ph.D., now science director at The Association. Bruijn says Cleveland “had a lot to do with my commitment to the ALS field.” His mentoring example led her to develop The ALS Association’s strategy of recruiting today’s promising young investigators.

Neurofilaments probably do play a role in ALS, as do other elements of the motor neuron and its neighbors. Just how it all comes together to kill a motor neuron is still unknown.

High Honor and Seminal Publication

Recently, Don Cleveland was elected to the National Academy of Sciences, which was founded by President Abraham Lincoln to serve as scientific advisors, a tradition continued today. Academy experts serve pro bono to address critical national issues and guide the federal government and the public.

Closely following this recognition by his peers was a seminal publication by his team in the journal *Science* highlighting the role of nearby cells as the motor neurons die in ALS. The report shows that microglia, the immune cells for the nervous system, are key players once ALS starts, at least in mice with mutation to SOD1. By selectively removing mutant SOD1 from microglia, Cleveland’s group produced SOD1 mice that lived a third longer, although time of disease onset did not differ from mice with mutation in all cells.

Candidate Therapy for SOD1 ALS

Cleveland envisions researchers might focus on improving the neighborhood around the cells dying in the disease, “an easier task than replacing a motor neuron,” he notes.

While scientists work toward such a strategy, Cleveland plans to try something that is available now for people with inherited, SOD1-mediated ALS. In the next year or so, a trial will test a compound called antisense that silences the defective gene. Safety trials are under way in large animals to confirm the acceptable nature of antisense delivered directly to the spinal cord.

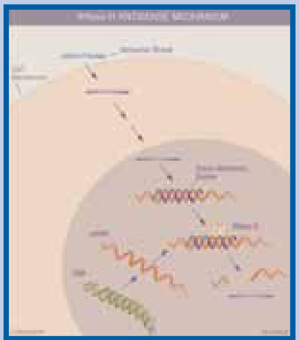


Image provided by Isis Pharmaceuticals

The Association has been the primary support of the antisense approach to ALS, from the basic science to the proposed clinical trial, Cleveland notes. “We already know that antisense agents in the rest of the body are safe,” he says, “we are optimistic it will be a credible basis for treatment of inherited ALS.”

To learn more about antisense visit http://www.alsa.org/news/article.cfm?id=999&CFID.

Patient Care Is Top Priority

A Conversation with The ALS Association's Vice President of Patient Services

Sharon J. Matland joined The ALS Association in 2005 as vice president, patient services with a diverse portfolio in health care management and consulting. She holds a master of business administration degree from Simmons College and a bachelor of science in nursing degree from Boston College. Matland is responsible for developing and providing programs and materials to build, expand, strengthen, communicate and promote The Association's patient services programs. In addition, Matland collaborates with the Community Services Department in developing and implementing patient services programs, working with The ALS Association Certified Centers of Excellence^{SM}, Chapters and ALS Clinics.

Sharon Matland, Vice President, Patient Services

HOPE: How does The Association's nationwide network for care help people and families affected by ALS?

MATLAND: The ALS Association has more than 20 years experience helping patients, families and caregivers. This experience allows our Chapters, Centers and Clinics to provide the highest quality services available to patients and to share best practices with each other. We continuously work to enhance communication between all of The Association's affiliates in order to improve and strengthen programs and services. Continued education of our personnel at Chapters and Centers is also an ongoing focus, and we are investigating new and improved ways to disseminate information to provide that education. In addition, we are exploring ways to more effectively reach people in unserved and under-served areas, which is a considerable challenge. To accomplish this, we are working to increase the number of Chapters, Centers and Clinics nationwide, as well as developing programs and alternative approaches to providing services that will reach an increased number of people with ALS and in addition, a more culturally diverse population. The integration of the expertise, programs and services across our Chapters, Centers and Clinics along with the commitment of those involved in fighting this disease pull together what we feel is one of the most comprehensive efforts to date in the fight against this disease.

HOPE: What is the prevalence of ALS in the United States?

MATLAND: It's estimated that there are 30,000 people living with ALS at any given time in the country. It is also estimated that every year there are 5,600 new cases of ALS diagnosed, and each year an estimated 5,600 people succumb to the disease. The fact that these numbers are estimates is a concern. Currently, there is a major initiative from the National Centers for Disease Control and Prevention, The ALS Registry Act, that was introduced in the House of Representatives and in the Senate. This bill would establish a national ALS registry that would collect information on the rate at which ALS occurs in the U.S. and the number of people living with ALS. This will not only allow gathering key statistics, but also identify the geographic regions where patients may be concentrated and better monitor the life styles and potential environmental exposures of people with ALS. Gender, age and other demographic information will also be captured. The hope is that gathering this information will help us better understand the disease process which will in turn help us develop treatments for ALS and eventually enable us to find a cure. The Association has been a major force to encourage the development of the Registry.

HOPE: What are some of the key components of The Association's patient services program?

MATLAND: The ALS Association has a nationwide network of

Diane Johnson, occupational therapist, and Sheila Tague*

Chapters, Certified Centers of Excellence and Clinics that co-ordinate care for people with ALS, their families and caregivers. The Chapters provide a variety of support including care management, equipment loan programs, support groups, information, and referral services and respite care. The Certified Centers use a multi-disciplinary team approach to treat patients, which has been documented in the literature as a way to improve the quality of life for those living with ALS. These teams include a neurologist, physical therapist, occupational therapist, social worker, registered nurse, speech language pathologist, and dietician and Chapter liaison. The Chapter liaison is typically a social worker or nurse and is the person responsible for the coordination of care for the person with ALS and their family and caregiver between clinic visits. The Center and Chapter dyad enables the delivery of a comprehensive, coordinated care program.

HOPE: What makes The ALS Association's approach so unique?

MATLAND: The Association's Chapters are community-based organizations that provide ongoing care services to people with ALS and their families and caregivers. These services are an integral part of the care for someone with ALS. Our Chapters can help those with ALS and their loved ones anticipate needs so that appropriate equipment and services are in place when they are needed. The Association's Certified Center of Excellence approach is unique because people with ALS see each member of the multidisciplinary team at each clinic visit. Each discipline spends an average of fifteen to forty-five minutes with a particular patient, depending on their needs. At the end of the day, a coordinated plan of care is developed that includes feedback from each of the team members. This coordinated approach to care is one way to make sure that the patient and the family have all the information they need in making important decisions regarding patient care.

> "The Chapter provides a liaison that is a member of the multidisciplinary team and helps to coordinate patient care between clinic visits."

HOPE: How do Chapters work with the medical community to establish new Certified Centers?

MATLAND: Typically, the Chapter introduces the concept of establishing a Certified Center to a neuromuscular neurologist and describes the Clinic and Center development process, which includes assembling the multidisciplinary team of licensed and certified ancillary service practitioners, establishing the interdisciplinary care model. In addition, there must be access to neurological diagnostics and imaging capability. Certified Centers have a minimum of fifty patients on their caseloads on an annual basis. The Chapter provides a liaison that is a member of the multidisciplinary team and helps to coordinate patient care between clinic visits. Patients are seen about every three months in the Clinic, and the Chapter liaison oversees the implementation of the patient care plan that is defined during the visit to the Center. This coordination is critical for the patient, family and caregiver so that treatment can be as effective as possible.

HOPE: How is The ALS Association helping families and caregivers in the area of respite care?

MATLAND: Respite care is incredibly important to everyone involved; the patient, the family and the caregiver. It provides the caregiver with a much-needed break, and both the caregiver and the person with ALS benefit in that a rested caregiver is able to provide better patient care. However, it's not unusual for the caregiver to be reluctant to leave the care of the patient in someone else's hands, and the person with ALS may not want their caregiver to leave. The ALS Association is working with the Langeloth Foundation on a pilot program called Care Connection. This is an expansion of a pilot done about three years ago with The Association's Greater Los Angeles Chapter where volunteers come into the home to provide care and services to the patient. A schedule is established and the volunteers sign up for a certain time period to provide certain services. The number of volunteers can be quite large, up to 60 to 70 volunteers.

HOPE: How the Care Connection program work?

MATLAND: Under the Care Connection, the Chapter works with the family to first identify a lead volunteer who will serve as the organizer, and by design, this is not a primary caregiver. The organizer will do the scheduling and coordinate with the volunteers to ensure all of the patient's needs are being met. The Chapter, in conjunction with the family, will provide orientation and training for the organizer on how to establish and monitor the program for the family. Next, a group of volunteer participants are identified. These volunteers will be providing the care and services to the patient. This coordinated care allows the primary caregiver to take a break and recharge in a

Lee Stevens; Jo Tanzer, Arizona Chapter patient services director, and Kathy Crowley, social worker*

Virginia Squire and Melissa Ponce, R.N.*

similar fashion to a respite care program. There is also an online mechanism called "Lotsa Helping Hands" that can assist with the coordination of a Care Connection. With five chapters in the current pilot program, we hope to expand the program across our nationwide network of Chapters.

HOPE: Would you please tell us about how this online service can help people setting up a Care Connection program?

MATLAND: There is a free web-based service, "Lotsa Helping Hands," that allows a designated person to coordinate friends, family, colleagues, and neighbors to assist loved ones in need, just as the "organizer" would in the Care Connection program, but this service is provided online. Lotsa Helping Hands is part of The Association's Care Connection pilot program, which provides tools and training to families on how to create networks, encourage people to get involved and coordinate care. Members are automatically notified with a listing of available opportunities in which they may participate and current commitments they or others may hold.

HOPE: What other programs are you developing?

MATLAND: Through a grant from the NEC Corporation, we are working on an augmentative/alternative communication program for our Chapters and Certified Centers that is a supplement to our ALSA Speaks! program, which helps people with communications needs. Augmentative/alternative communication is vitally important to people with ALS because as the disease progresses, most people with ALS lose their ability to speak. Via this grant, The Association will provide training to Chapter and Center personnel at regional meetings and using webcast technology. Another exciting project currently in development is a respiratory symposium The Association will be hosting in January 2007. With the support of a grant from the Will Rogers Institute, this symposium will educate pulmonologists, neurologists, respiratory therapists and allied health professionals by providing the latest information on respiratory issues and research as they relate to ALS and an opportunity for professionals in this field to interact and exchange ideas about respiratory care.

> People need to be aware of their options and our goal is to help them to do that.

HOPE: Tell us about The Association's Clinical Management Research Grant Program and the relevance to ALS.

MATLAND: The Clinical Management Research Grant program, that began in 1998, provides funding for the study of certain areas such as nutrition, respiration and the psychosocial factors associated with the disease. Typically, two grants are awarded each year, and the program is administered with the assistance of a clinical/medical Committee comprised of ALS neurologists, epidemiologists and allied health professionals.

HOPE: What is the objective of the Clinical Management Research Grant program?

MATLAND: Our primary objective is to provide clinicians with an opportunity to conduct smaller research studies. A number of these grants have been awarded to medical directors from The Association's Certified Centers of Excellence. Our grants do, however, fund studies across the United States as well as internationally.

HOPE: What is on the horizon as far as improving patient care for the future?

MATLAND: There are many things that are being researched now that we anticipate will have an impact on increasing the length of time someone with ALS can live. Not only have there been advances in augmentative/alternative communication for example, but there have also been advances in respiratory technology, equipment technology and in overall patient care, including the care provided by our Chapters and Centers. Studies have shown that people who experience an improved quality of life live longer. The interventions mentioned above all provide patients with strategies to keep them as independent as possible for as long as possible. This in turn has resulted in a higher quality of life and therefore longer life. There are also new technologies being developed such as brain computer interface technology. It is hoped that these types of advancements will do more in the years to come to continue to extend life and improve the quality of life of those that live with ALS. Medications are being researched that could have a dramatic impact on improving clinical symptom management. Beyond research and improved technology, just being able to reach more people and connect them with The Association's nationwide network of Chapters and Centers opens the door for more people to take advantage of all The Association and medical science has to offer. It all begins with outreach and education. People need to be aware of their options, and our goal is to help them to do that.

Richard Keiss and Todd Levine, M.D.*

*Photos taken at Banner Good Samaritan Regional Medical Center ALS Clinic in Phoenix, Ariz.

Care Connection
Supports the Entire Family

By Katie Sweeney

Editor's note: One August 30, Anne Keeler, who is profiled in this article, passed away. The family asked that we publish this article as planned with the hope that others can benefit from Anne and Gordon's experience. The ALS Association extends its deepest sympathy and gratitude to the Keeler family.

When Gordy Keeler goes to work each morning, he knows his wife, Anne, is in good hands—thanks to a special group of volunteers who have helped care for her since she was diagnosed with ALS in July 2003.

The group involves 40 people who take turns coming to the Keeler home in Eagan, Minn., to care for Anne or to take care of shopping or other tasks that Gordy no longer has time for.

"Without these wonderful people, my daughter, son and I would be doing everything ourselves," says Gordy. "I don't know how we would have made it."

> "Without these wonderful people…I don't know how we would have made it."

Such volunteer networks can be a great way to help share the many tasks involved in caring for someone with ALS. That's why The ALS Association recently began a new pilot program to help more families establish these networks in their own communities.

Care Givers helping Anne with sling lift (Friday AM Care Givers) Left to right: Noreen Dean, Marsha Nelson, Mary Borrmann

The ALS Association's Care Connection Program will provide tools and training to families on how to create networks, encourage people to get involved and coordinate care. The program will also include special training for volunteers on what ALS is and how to interact with patients and families. The pilot will involve five chapters, but the goal is to eventually take it nationwide to all chapters.

"Caring for someone with ALS is a 24/7 job," notes Sharon Matland, R.N., M.B.A., and vice president of patient services for The Association. "We're hoping this program will give more caregivers access to the respite and assistance they need."

The Care Connection Program is a continuation of a smaller pilot program The Association started in 2004. Under that program, the Greater Los Angeles Chapter has held special training sessions and helped several families establish successful caregiving networks. Both pilot programs have been funded by grants from The Langeloth Foundation.

> "They're truly making a difference in someone's life."

The program is based on "Share the Care: How to Organize a Group to Care for Someone Who is Seriously Ill," a book by Cappy Capossela and Sheila Warnock. That book is also what inspired Gordy and Anne Keeler to set up a caregiving group three years ago with some help from the Minnesota Chapter. At the time, Anne was newly diagnosed, and they sent emails to friends and family members asking if they were interested in helping.

Keeler family son Brian, husband Gordon, Anne and daughter Bonnie with Sadie.

More than 40 people showed up in their living room for a start-up meeting. Some were family members and close friends, but other volunteers have been more surprising: parents of their son's baseball teammates, friends of friends, former co-workers. Some they had never met before.

Initially, volunteers served mostly as companions, taking Anne to an occasional movie or helping with household chores. As her disease progressed, they began doing more intensive personal care tasks.

Today, Anne's ALS is advanced, and she is dependent on her caregivers 24 hours a day. A core group of about a dozen volunteers divide up the day-to-day care when Gordy is at work. The remaining volunteers help with such tasks as cooking, grocery shopping, yard work and helping to schedule and organize volunteers each week. The Keelers' two adult children, Bonnie and Brian, also help with Anne's care.

Caregivers meet to organize care for Anne

"Initially, Annie and I struggled with allowing people to do things for us," Gordy says. "But nobody has to do anything they're not comfortable doing. And it's been great for Annie. She really looks forward to seeing these people."

He recommends forming a group as early in the ALS process as possible. "We've grown together," Gordy explains. "It's been really heartwarming for us and for the volunteers, too. They've learned they can do things they never thought they could do. They're truly making a difference in someone's life."

Advocacy in Action
Throughout the Year

By Patrick Wildman, Director, Communications and Public Policy

It's fall. The leaves are turning, the kids are back at school and winter is just around the corner. It's not the time of year most people in the ALS community associate with advocacy. After all, National ALS Advocacy Day in Washington, D.C., the single largest gathering of the ALS community, does not take place until May, many months from now.

What many people do not realize is that advocacy is a year round activity and that Members of Congress consider issues of importance to the ALS community throughout the year – spring, summer, winter … and fall. And as issues such as appropriations bills that fund ALS research move through the legislative process, it is important that Members of Congress hear from the people most impacted, their constituents, at key stages during the year.

> "Advocacy is a year round activity."

The ALS Association has an exciting online service that allows the ALS community to deliver their message to Congress at the click of a mouse. The Advocacy Action Center, which can be found in the Public Policy section of www.alsa.org, includes a number of vital tools. For example, the site:

- Enables advocates to easily identify their Members of Congress simply by typing in their zip code or clicking on a map of the United States. The feature also provides contact information for every Member of Congress as well as links to their web sites;
- Empowers advocates with the ability to easily contact their Members of Congress through the availability of talking points and sample letters that can be sent directly to Congress using the web site. The letters can be personalized and sent to Congress via standard mail or e-mail;

- Educates advocates about current advocacy issues through the Action Alert section of the site. The "Capitol Hill Basics" section of the site also provides information on the legislative process, visiting Capitol Hill, the roles of various Congressional staff, and tips on communicating with Members of Congress;
- Enhances the ability of advocates to generate grassroots support and awareness of ALS issues by permitting visitors to share nearly every section of the website, including Action Alerts, using the "Tell A Friend" feature; and
- Provides visitors the opportunity to enroll in the The ALS Association Advocate program and receive timely updates and Action Alerts on the latest advocacy issues. E-mail Action Alerts received via this service are linked directly to the Advocacy Action Center so that recipients can send letters to Congress simply by clicking on the Action Alert.

> They can take action and deliver The Association's message to Capitol Hill when it's needed most.

The Advocacy Action Center is a key component of The Association's comprehensive advocacy strategy. "In order to effectively deliver our message, we need to make sure Congress hears from the ALS community throughout the year," says Steve Gibson, vice president of government relations and public affairs. "These tools provide PALS and families an easy way to do that – to tell the ALS story on Capitol Hill and develop the relationships with Members of Congress that are so critical to advancing our cause."

Since the site was first introduced last year, thousands of people from across the country have used it to contact Congress. In fact, individuals from every state in the country have sent letters from the web site, helping to give a voice to those in the ALS community. Others have used the site to spread the word about ALS issues and to recruit friends and colleagues to join the fight against the disease. And more than 1,400 have signed up as The ALS Association Advocates so they can stay informed on the issues impacting the ALS community and, more importantly, so that they can take action and deliver The Association's message to Capitol Hill when it's needed most.

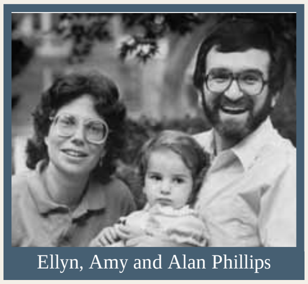
"This is critical," says Gibson. "When the House or Senate schedules a last minute vote on an appropriations bill, we can mobilize our advocates – our key contacts – to reach out to their Members of Congress immediately. It has a tremendous impact and makes an enormous difference in the effectiveness of our advocacy."

> "We can mobilize our advocates… makes an enormous difference in the effectiveness of our advocacy."

The Advocacy Action Center, available at www.alsa.org/policy, truly enables the entire ALS community to advocate at the most important times of the year, whether it is spring, summer, winter or fall.

Fighting ALS is a family affair

By Daniel Gonzales, Development Communications Associate



Ellyn, Amy and Alan Phillips

For Ellyn Phillips, 1982 was the best of times and the worst of times. She was married to Alan, the man of her dreams, and they were proud parents of a beautiful baby girl. Ellyn describes Alan as an extremely energetic and brilliant person who wrote for the *Philadelphia Inquirer* with the goal of becoming an investigative journalist. Instead he switched careers to become a lawyer and worked for Community Legal Services helping people in need. Everything seemed to be going picture perfect for both of them until Alan, who enjoyed playing basketball and baseball in his spare time, started having trouble during his basketball games.

"I couldn't imagine that over 20 years later we would still be fighting this disease."

"For three weeks in a row, Alan started coming home earlier and earlier because he just wasn't making any points," explains Ellyn of her husband's first symptoms of amyotrophic lateral sclerosis (ALS). "When baseball season started, he went from being one of the best hitters to the worst. The team even moved him from second base to the outfield." The pivotal point in their lives came when Alan tried to throw a baseball, and it fell out of his hands, landing behind him.

"I knew Lou Gehrig had a terrible disease, but I didn't know much about ALS before Alan was diagnosed," Ellyn shared. At first her parents, Morton and Malvina Charlestein, were in shock, but they quickly became actively engaged to help their daughter take care of Alan and their 16-month-old granddaughter, Amy. After a difficult two-year struggle, Alan lost his battle with ALS, but Ellyn's parents continued the fight by forming The Philadelphia Friends of ALS. This was a fundraising group they started with another couple, Teri and Howard Abrams, which eventually became part of the National ALS Foundation's Philadelphia Chapter. Soon thereafter, Ellyn became president of the chapter and later joined her father as a Trustee for the newly formed ALS Association in 1986.

As Ellyn recalls, "At the time I was unrealistic about how long it would take to understand, treat, and conquer ALS. I couldn't imagine that more than 20 years later we would still be fighting this disease." But thanks to the support of her parents, especially her mother, Malvina, who was instrumental in forming a fundraising relationship with the Philadelphia Phillies, she transformed a struggling chapter with an initial budget of $5,000 to one of The ALS Association's most dynamic and flourishing chapters. "Becoming the most successful chapter didn't just fall in our laps. It has taken many years of hard work to get to where we are today. I am extremely proud that our chapter has become a role model for others to follow."

In addition to the success of the Greater Philadelphia Chapter, Ellyn also devotes much of her time serving as a member of The ALS Association's National Board of Trustees and Chair of The Association's Advocacy Committee. As Ellyn explains, advocacy has an enormous impact for the thousands of people battling ALS. "The success we had in the past few years has made living with ALS better. I love going to Advocacy Day and seeing all the people with ALS, caregivers and family members. They have accomplished so much, and they feel so great about what they are doing."

In a remarkable gesture of generosity, Morton and Malvina recently gave a $500,000 gift to support The Association's advocacy efforts, the Greater Philadelphia Chapter and to establish The Alan L. Phillips Discovery Grant Award. This grant honors Alan's legacy by supporting new investigators entering the field of ALS research who propose innovative projects likely to provide important results relevant to the study of this disease. The tremendous impact that ALS has had on Ellyn and her family has even lead to the passing of the torch to a third generation in the Phillips' fight against ALS.

At last year's National ALS Advocacy Day and Public Policy Conference, Ellyn's daughter, Amy Phillips, gave a heartwarming speech about her father and the importance of raising awareness and funds to find a cure. But as Amy puts it, there's more to advocacy than just that, "It's also about helping people with ALS and their families realize that there is a support network out there… that they're not alone." Amy followed her father's footsteps as a journalist and currently is a news editor for an online music magazine. According to Ellyn, Amy is incredibly supportive of everything her mother has worked to achieve.

Ellyn, Amy with Malvina & Morton Charlestein

The ALS Association's President and CEO, Gary A. Leo, recently commented on the remarkable contributions that Ellyn and her parents achieved to make The ALS Association what it is today. "They have done an incredible job in advancing us to the level that we are at with regard to research, patient care and advocacy. They are a true inspiration to all of us here, but more importantly, to the thousands living with this dreadful disease."

The greatest life lesson Ellyn learned from Alan was to appreciate everything in life and to live every day like it is your last. It is words of wisdom like this that has kept her focused, dedicated and going strong for the last 22 years, and with all of that she has great optimism for the future. "I'd like to see us well on the way toward viable treatments, more funding from the government, and more beneficial patient care." For Ellyn Phillips and her family, the destructive nature of ALS has allowed them to create hope for countless patients and families across the country. Her impact on the fight against ALS has paved an important pathway that definitively serves as a foundation for the future and hope for generations to come.

New Programs to Honor and Show Appreciation


“ALS advocate and 2006 Miss National Sweetheart, Amanda Watson, started an online Tribute Fund in memory of family members who passed away from the disease.”

The ALS Association has introduced two new programs designed to raise awareness about ALS and to increase support for the fight against this devastating disease. The first of these programs is The ALS Association’s Community of Hope, which allows family and friends to create online tribute funds in memory or in honor of an ALS patient, loved one, or for any special occasion such as a wedding or graduation.

For instance, Amanda Watson, the 2006 Miss National Sweetheart and ALS advocate, started her own tribute page at http://web.alsa.org/goto/AmandaWatson in memory of her grandfather and great-grandfather who both passed away from ALS.

“I think starting a tribute page is one more way that the public can get involved with the fight against ALS,” explains Amanda. “Since most people use the Internet as a main source of communication, this is an excellent way to reach the greatest number of people.”

“I think starting a tribute page is one more way that the public can get involved with the fight against ALS.”

People like Amanda who create tribute funds can easily add information regarding the honoree, upload photos, track the number of gifts and see who is giving through the website’s user-friendly format. No matter what knowledge of computers or the Internet a person may have, The ALS Association’s Community of Hope is easy-to-use and maintain for the most advanced to the least experienced.

As Amanda explains, having a tribute fund can prove to be a powerful tool to help those living with the disease. “If people can read personal stories from the hearts of those who have been affected by the disease, they might be more inclined to become part of the Community of Hope.”

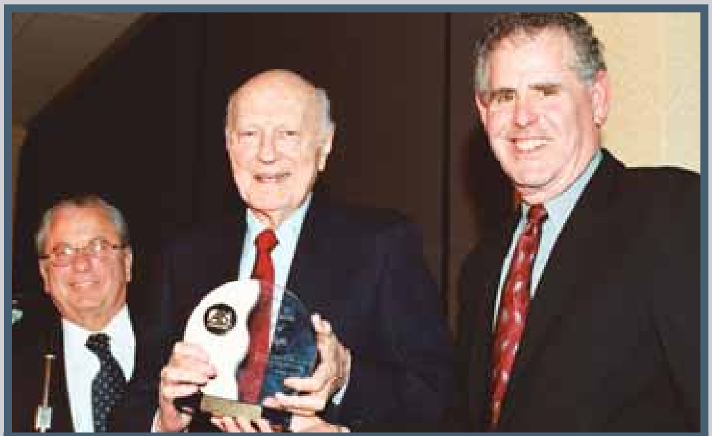
Another new program is The ALS Association’s Circles of Giving, which was created in an effort to show appreciation to those who have supported The Association throughout the years. This donor recognition program consists of six distinct circles of appreciation starting at the $25,000 level. Each circle represents a milestone in the donor’s overall giving, and a unique award is personally presented to them as a level in the Circles of Giving is reached.

According to The ALS Association’s President and Chief Executive Officer, Gary A. Leo, the Circles of Giving program is an excellent way to say thank you, recognize the donors commitment and gain more support for The Association’s research, patient services and advocacy efforts. “This program not only shows our appreciation to those generous people who have helped build this organization into what it is today, but it can also take their giving to the next level which would have an enormous impact on patients, families and our research programs.”

This impact would further benefit courageous ALS patients like Patrick Carney who relies on The ALS Association for his best source for information, patient services and hope. As he explains, “Learning how to live with ALS has taught me to savor moments with my family, live mainly in the present, and try to find the humor in happenings – both positive and negative.”

Another facet of the program is an online donor wall located at http://www.alsa.org/donate/circles.cfm that has been created to further recognize award recipients and to serve as a permanent tribute for their support. As Leo explains, “We wanted to make certain that The Association supporters know how much their giving means not only to us, but to the brave people who remain positive and full of spirit while living with this unforgiving disease.”

The ALS Association is confident that the Community of Hope and the Circles of Giving programs will increase awareness, help improve the lives of people with ALS and further support funding to find a cure. For people like Amanda Watson and Patrick Carney, these programs will give them comfort and provide optimism that ALS will one day be a disease of the past. If you would like more information on these programs, call toll-free 1-888-949-2577.


“Larry Barnett (center), a founding Association Trustee, receives the prestigious Circle of Life award from Chairman Allen L. Finkelstein (left) and President Gary A. Leo (right).”

-D. G.

LIVING WITH ALS

Artist Remains at the Easel in Spite of ALS

By Stephanie Dufner, Communications Coordinator

Peggy Chun

The vividly colorful creations of Hawaii-based artist Peggy Chun feature a variety of themes including rock-strewn tropical landscapes, verdant palm trees and the sea foam green hues of the Pacific.

"Hawaii is one of the most beautiful places on earth," Chun admits. "My love of intense color made everything here excellent subject matter."

A resident of Nuuanu Valley in Honolulu, 60-year-old Chun has lived with ALS since spring 2002. Born in Oklahoma, she began her artistic career in the late 1980s under bittersweet circumstances.

"My identical twin sister, Bobbie, was a nationally renowned pastel artist. She was the artist in the family until she died of ALS in 1987," reveals Chun. Six months after Bobbie's death, Chun "woke from a dream with an urgency to paint." In addition, Chun is not stranger to ALS as her mother and grandfather also passed away from the disease.

Celebration in the Banana Patch
by Peggy Chun

Chun's vision led her to the Honolulu Academy of Arts where she met her mentor, Gloria Foss. "She encouraged me…and taught me the most important elements of painting so that I had the courage to become a professional artist," Chun says.

Despite having ALS, Chun continues to pursue her beloved craft. After learning she had the disease, she continued painting with her right hand for the next 10 months. When she lost the use of her dominant hand, Chun discloses her left hand "immediately took over." Using her left hand allowed Chun to paint in a "looser style" as opposed to the realistic manner in which she and her followers were accustomed. It was about this time that she began using a ventilator.

In 2004, this looser technique evolved into a more impressionistic painting style once Chun could no longer paint the canvas with her left hand. For a while, she painted with her teeth, but eventually her jaws were unable to control the paintbrush.

With the exception of this eye movement, Chun's body is now completely paralyzed. Fortunately, modern technology has given the painter the ability to remain in front of the easel. An eye response computer system allows Chun to paint with her eyes through the use of an onscreen keyboard. "At this time, I'm experimenting with limitless color combinations and the shapes that result from my eye control of the cursor." Chun continues, "I'm working with a company to paint with my brain waves and have already completed several paintings! My love of color provides the subject matter."

Eye Heart You
by Peggy Chun

Chun's daughter-in-law, Kimi Morton Chun, has seen the evolution in Chun's paintings in the past few years. "She really seemed to make each transition over night," states Morton Chun, who serves as CEO of Peggy Chun, Inc., and manages the company's finances and administrative components.

The artist's extended family has helped her to adjust to these new painting methods. At night, Chun relies on private caregivers to administer to her physical needs, but during the day, a group of friends and family aptly named "Peg's Legs" work three shifts to care for the artist. Those involved in this group do everything from managing Chun's ventilator and performing light household tasks to assisting her with her artwork.

In addition, physical challenges have not stopped Chun from teaching art to students whose ages range from two to 90, an activity she describes as "fearless fun." "I write the lessons, and family and 'Peg's Legs' do all the work—they certainly do make me look good," says Chun. As for her own artwork, Chun's painting assistants follow her written instructions to assemble mosaics.

Peggy Chun Teeth Painting

"I'm able to live happily with ALS because my support system allows me to create, paint and contribute financially," Chun acknowledges.

To see Peggy Chun's artwork, visit her website at www.peggychun.com.

The ALS Association's eStore opens this fall. The store will be selling a calendar for 2007 that features Chun's work. To order this calendar, visit www.alsa.org/news/article.cfm?id=1000.

The Greatest Gift

A parent's love for their child is the greatest of human emotions, and it forms one of the strongest bonds imaginable. The love Don and Mary Lois Long had for their son, Jeff, gave them the strength to cope and persevere with any challenge that life threw at them – including ALS.


Don Long

In 1985, Don and Mary Lois were in their late 60s and ready for retirement when they received the devastating news that Jeff had been diagnosed with ALS at the age of 36. Like many people with Lou Gehrig's disease, Jeff was an athletic person who was an accomplished gymnast in college, specializing in the parallel bars. After he graduated, Jeff started a successful retail shoe business, got married, and had three children. Jeff's wife was a nurse who knew exactly what ALS did to patients and families. She decided it would be too much for her to handle, and she subsequently filed for a divorce.

According to Don, Jeff handled his heartbreaking turn of events the best he could. "Jeff was an unusual young man in that he was even-tempered. He accepted his fate and did the best he could to get the most out of life." To be close to his kids, Jeff bought a house for his ex-wife and their children a few miles away, but now he had to face this unforgiving disease alone. Putting their retirement plans on hiatus, Don and Mary Lois moved to Kansas City from Columbia, Missouri, to be with their son and assist in his care, as well as provide emotional support for their young grandchildren.


Circa 1981, four generations of the Long family: from left, Don, father Clarence (seated), grandson Ben (baby) and son Jeff, who passed away in 1990

This was the beginning of the Long family's fight against ALS. During the years they cared for Jeff, Don and Mary Lois became heavily involved with the Keith Worthington Chapter of The ALS Association. They made donations, helped with newsletters, mailings, events, and even visited other ALS patients. Eventually Don was elected to the chapter's Board of Directors, and he brought a sense of realism to other members of the Board because of his first-hand experiences with the disease.

In the winter of 1990, Jeff lost his battle with ALS. "That morning he wanted to tell me something, but he just couldn't do it. He laid back and peacefully passed away," recalls Don of his son's final moments. After five years of caring for their son and grandchildren, Don and Mary Lois continued their son's legacy in Arizona by founding The ALS Association's successful Valley of the Sun Chapter, now known as the Arizona Chapter.

Mary Lois has since passed away. Although Don is no longer active with the chapter, he still continues his family's legacy by contributing to The ALS Association through a charitable gift annuity. With this financial arrangement, Don transferred some assets to The ALS Association, which The Association reinvested. In return, Don receives fixed income payments from The Association for his entire life, after which the funds are available for use in the fight against ALS. In addition, Don received an income tax charitable deduction the year he established his gift annuity.

"I know the money given to The ALS Association will be used for the betterment of ALS patients," explained Don on why making gifts to The ALS Association is so important for those living with this disease. His impact on the ALS community has been immeasurable, but the greatest gift Don ever gave was being there when his son needed him most.

Payments made under a charitable gift annuity are backed solely by the full faith and credit of the issuing organization, are not insured or guaranteed by an insurance company, are not protected by any insurance guaranty association, and are not backed in any way by the states.

To find out how a charitable gift annuity can benefit you, contact Juan Ros, The ALS Association's Director of Gift Planning at (888) 949-2577, ext. 212, or via e-mail at juan@alsa-national.org. You can also learn more about gift annuities in the Gift Planning section of The Association's web site at www.alsa.org/giftplanning. All inquiries are strictly confidential.

–D.G.

New Tax Law Allows Charitable Gifts from IRAs

In considering your charitable giving plans, we want you to be aware of a provision in the recently-signed Pension Protection Act of 2006. This new law permits tax-free charitable transfers of up to $100,000 per year from IRA accounts to qualifying charitable organizations, including The ALS Association, during 2006 and 2007.

To qualify, donors must have reached age 70½ by the date of contribution. This exclusion applies only to traditional and Roth IRAs. Other retirement plans such as 401(k), 403(b), SEPs, and SIMPLE plans are not eligible.

For more information, please contact your tax advisor or The ALS Association's Office of Gift Planning toll-free at (888) 949-2577, extension 212, or via e-mail at giftplanning@alsa-national.org.

Attention:

Office of Gift Planning

☐ I am interested in learning more about charitable gift annuities. Please contact me.

☐ I would consider remembering The ALS Association in my will, trust, or other estate plan.

☐ I have already remembered The ALS Association in my will, trust, or other estate plan.

Name: ______________________________

Mailing Address: ______________________________

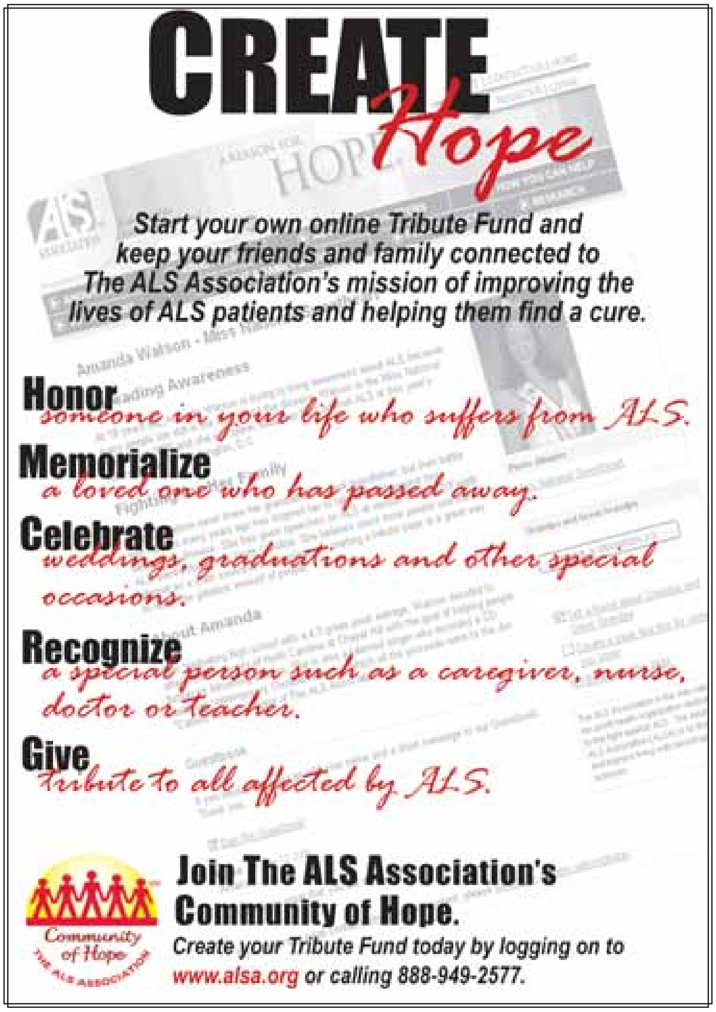
City: ______________________ State: __________

Zip: ______________________________

Phone number: ______________________________

E-mail: ______________________________

Mail the completed form to: Director of Gift Planning,
The ALS Association,
27001 Agoura Road, Suite 150, Calabasas Hills, CA, 91301-5104,
or visit www.alsa.org/gift planning or fax to: (818) 880-9006.



CREATE *Hope*

Start your own online Tribute Fund and keep your friends and family connected to The ALS Association's mission of improving the lives of ALS patients and helping them find a cure.

Honor *someone in your life who suffers from ALS.*

Memorialize *a loved one who has passed away.*

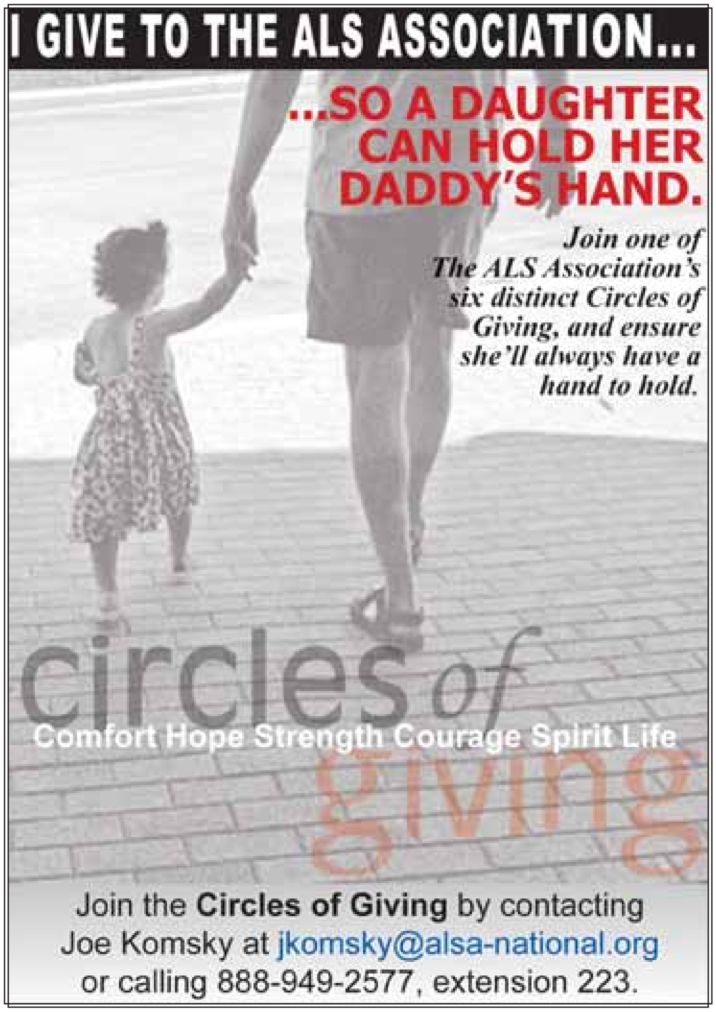
Celebrate *weddings, graduations and other special occasions.*

Recognize *a special person such as a caregiver, nurse, doctor or teacher.*

Give *tribute to all affected by ALS.*

Join The ALS Association's Community of Hope.

Create your Tribute Fund today by logging on to www.alsa.org or calling 888-949-2577.



I GIVE TO THE ALS ASSOCIATION...

...SO A DAUGHTER CAN HOLD HER DADDY'S HAND.

Join one of The ALS Association's six distinct Circles of Giving, and ensure she'll always have a hand to hold.

Join the **Circles of Giving** by contacting Joe Komsky at jkomsky@alsa-national.org or calling 888-949-2577, extension 223.

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