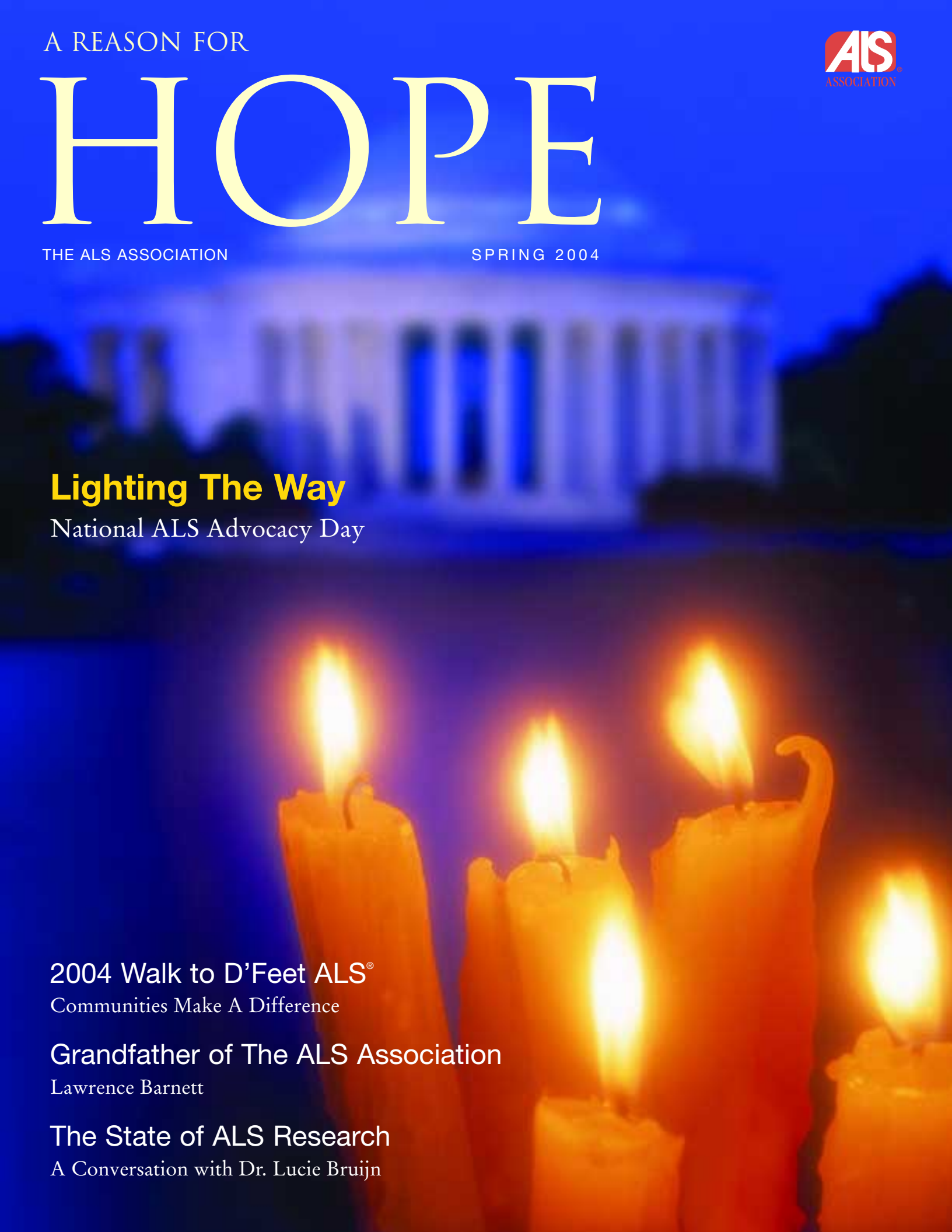
A REASON FOR

HOPE

THE ALS ASSOCIATION

SPRING 2004



Lighting The Way

National ALS Advocacy Day

2004 Walk to D'Feet ALS®

Communities Make A Difference

Grandfather of The ALS Association

Lawrence Barnett

The State of ALS Research

A Conversation with Dr. Lucie Bruijn

A REASON FOR

HOPE

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ABOUT THIS ISSUE... A Reason for HOPE is the new magazine of The ALS Association. In the pages of HOPE, we will feature articles and interviews that will cast a revealing light on subjects foremost in the minds of people who are living with ALS and their families, loved ones and caregivers.

We will provide important perspectives from those closely involved in shaping the discussion about the disease taking place in Washington, D.C., as well as state capitals and communities across the nation. This month's cover story outlines ALSA's 2004 legislative priorities and describes upcoming advocacy activities during National ALS Advocacy Day and Public Policy Conference including the candlelight vigil at the Jefferson Memorial.

HOPE will provide insight into the latest advances from the frontlines of research and patient care. You will hear from the experts about today's innovative research projects being conducted by some of the world's foremost investigators.

We will focus on the work of ALSA's chapters that work tirelessly to deliver support and services to patients and families. In addition, you will receive an update on vital initiatives, such as The Walk to D'Feet ALS® and many community awareness activities.

For your convenience, HOPE will be available electronically via e-mail and on ALSA's web site. We encourage readers who would rather receive the publication electronically to contact us at HOPE@alsa-national.org.

Through it all, we will tell the stories of those who represent the thousands of people in the ALS community, including patients, families, caregivers and everyone dedicated to providing "a reason for hope." We invite your comments and suggestions regarding the publication.

The ALS Association is committed to leaving no stone unturned in the quest to find treatments and discovering a cure. We truly believe that "fighting ALS is a full time job."

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Vice President,
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Editor & Director,
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THE ALS ASSOCIATION SPRING 2004

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A TOTAL APPROACH TO CARING

By Jennifer Brand & Kristin Thébaud

A strong relationship between local chapters and ALSA centers is one example of how The ALS Association provides comprehensive programs and services.

As Judy Fisher and her husband traveled to their first appointment at the local certified ALSA Center in March 2003, fear of the unknown settled in as she thought about her ALS diagnosis. Upon arrival, they discovered that the atmosphere was warm, welcoming and friendly, with people from The ALS Association South Texas Chapter greeting them at the door.

"I didn't know what to expect," Fisher said. "But I found all the people who worked there to be so caring. They care about me and my family, and they always want to see pictures of family and grandchildren."

The ALS Association applies a rigorous certification process and, thus far, has certified 19 ALSA Centers in distinguished institutions across the country. These centers of excellence work closely with local ALSA Chapters to provide emotional and physical health care to people with ALS and their families. In addition, chapter patient services staff provides a variety of support such as referral services, education and facilitating an equipment loan program.

"Chapter patient services staff include credentialed health care specialists who provide expert services and programs to both individuals and groups," said Mary Lyon, vice president of patient services in ALSA's national office. "Working in conjunction with ALSA Centers, these caring professionals help to ensure that each person maintains the highest quality of life possible."

Kristin Bonilla, South Texas Chapter patient services coordinator, said their local ALSA Center serves 105 people with ALS, but only about seven participate in each clinic session so that the staff can focus on each person. Because some patients travel five hours to get to the center, Bonilla emphasizes the importance of meeting all their needs in one place.

Chapters provide a comprehensive range of patient services, including resource and referral services via phone, web site and e-mail; newsletters; resource guides; equipment loan and referral programs; and ALS education symposia for patients, families and health care professionals. Print materials cover a number of general and specific topics and include ALSA's Living With ALS® manuals and videos, fact sheets, brochures and booklets. Chapters also offer support groups that provide everyone involved with an opportunity to meet other people struggling with the same issues and to discuss practical care issues.

Many chapters provide other specialty services, such as respite care, transportation, case management and alternative augmentative communication programs. Also, special interest programs and services are available that include psychosocial/spirituality, support for newly diagnosed families, clinical drug trials and treatment development, family caregivers, children's education and activity programs, and end-of-life care and related information. The ALS Association sponsors a clinical management grant program that funds research into improving the quality of life for people with ALS.

The Greater Los Angeles Chapter loaned David Rozzen a voice output keyboard communication device that allows him to communicate. Normally costing $2,000, Rozzen has the use of this device at no cost to the family.

"The machine has become a conversation piece," Rozzen said."Young children think it's a toy and want me to show them how each of the buttons work. It really allows me to speak to people."

Linda Madole, augmentative alternative communication program director, demonstrates communication device to David Rozzen as wife Marian and son Brian observe

Ann Ver Planck, director of patient services at the Greater Los Angeles Chapter, has also helped to develop a solid case management program. Each patient identified in their service area is assigned a case manager and is personally contacted.

Rozzen's wife Marian described the difference that case management has made in dealing with the disease, explaining that she called the chapter office when her husband was first diagnosed and immediately received a phone call from their case manager, who came to the Rozzen home to speak with the family.

"Patient Services is really a relationship service," Lyon said. "People in the chapters work to develop caring and personal relationships with people in the ALS community so that they can meet their specific needs. That's how we continue to deliver a myriad of care."

"People don't always know when they are going to need to talk to someone," Ver Planck said. "We want every person with ALS to have a case manager so they know ahead of time who to call."

PUBLIC POLICY INITIATIVES

LIGHT THE WAY

By Kristin Thébaud

Shelbie Oppenheimer can no longer lift her finger, but she can still hold a candle to anyone on Capitol Hill. And this May, she will.

On May 18, advocates will gather on Capitol Hill to fight for legislation that affects people living with ALS. They will begin on May 16 by each raising a candle on the steps of the Jefferson Memorial in Washington, D.C., in memory of loved ones gone and to honor the presence of those people who continue to live with the disease.

"This candlelight vigil will be a time and a place for us to reflect on why we gather in Washington each year," said Steve Gibson, vice president, government relations and public affairs. "As we gather the night before we go to the Hill, we will renew our strength together and focus our energy."

The vigil is the inspiration for this year's public policy theme, "Lighting the Way for a Treatment and Cure." Advocates from ALSA chapters across the nation will gather May 16-18 for the annual conference, which is expanded to 3 days this year. They will plan for meetings with legislators, attend public policy workshops and visit with legislators to discuss the issues important to the ALS community.

Oppenheimer understands that you can make a difference by testifying before a congressional committee. This demonstrates that while the number of people with ALS may be small, the need is great.

"It's important for all of us to feel a sense of empowerment," Oppenheimer said. "When we meet with our legislators, we show them that there is a face behind the illness. We're not just numbers."

Dean Rasmussen, a member of ALSA's National Board of Trustees and co-chair of the Advocacy Committee, believes National Advocacy ALS Day is one way that people with ALS feel a sense of purpose.

"One problem with ALS is that people eventually lose their voice," Rasmussen said. "But National Advocacy Day gives people with the disease a voice, and it helps people be heard at the highest level of government."

At the beginning of each year, the Advocacy Department conducts a "listening tour" to learn the public policy concerns and priorities of every ALSA chapter. When ALSA's new fiscal year begins, the Advocacy Department develops a coordinated strategy by identifying members on the congressional committees that have jurisdiction over those priorities. Then they begin matching ALSA advocates with legislators from those districts.

"Advocacy is really a science built on relationships," Gibson said. "We don't necessarily see more change in Congress based on the number of people who attend, but we do see more change as relationships are built between legislators and their constituents who have been touched by ALS."

This year, when advocates descend on Capitol Hill, they will discuss The ALS Association's 2004 legislative priorities, which focus on federal research dollars and reforming Social Security regulations that affect ALS patients. Research-related goals this year are to expand research at the National Institutes of Health (NIH), asking for an eight percent increase in funds, and to increase funding at the Department of Defense (DOD).

Steve Gibson consults with actor and advocate Blair Underwood.

Another goal that builds on last year's effort, which resulted in the Social Security Administration (SSA) issuing a presumptive disability ruling for people with ALS, is to have the five-month waiting period waived for people diagnosed with ALS. In the past, people with ALS were forced to go through rigorous bureaucratic procedures to determine if they were eligible for disability. Now, a person is automatically considered disabled once they have received a confirmed diagnosis of ALS. If the waiting period for those benefits is waived, people with ALS will receive their benefits almost immediately.

Gibson emphasizes that the priorities ebb and flow as new issues arise, noting that legislative issues are dealt with throughout the year, not just around National Advocacy Day.

Wayne Arnold, a Minnesota advocate with ALS, has been coming to National Advocacy Day for years and has seen change in NIH, DOD and SSA practices. "When people come out for Advocacy Day, it demonstrates to government agencies that there are a lot of people living with ALS, and we are willing to mobilize our efforts for the cause," Arnold said. "And it works."

Rasmussen has witnessed the impact on politicians when people with ALS present testimonies.

"A lot of people in Congress are not familiar with the disease, and when they see someone with ALS from their own district, it really brings it home for them," Rasmussen said.

Ellyn Phillips, a member of ALSA's National Board of Trustees, co-chair of the Public Policy Committee and Philadelphia Chapter Board president, agrees. She described a touching incident when Shelbie Oppenheimer was speaking during a televised National Advocacy Day hearing.

"As Shelbie explained the disease to Sen. Arlen Specter (R-Pa), suddenly her three-year-old daughter Isabel broke loose from her father and ran up to sit on Shelbie's lap," Phillips said. "While Shelbie continued to talk about the challenges she faces each day living with ALS, Isabel played with her mother's pearls."

"That was a big moment for me, too," Oppenheimer agreed. "I realized that this was a reminder to all of us and to the legislators that each of us living with ALS is a vital part of our families and communities."

Sarah Wood, a member of ALSA's National Board of Trustees and president of the Western Pennsylvania Chapter Board, thinks that a large turnout of advocates attending National Advocacy Day makes a strong impression on the people with ALS who have come to Washington, D.C. She spoke of one man with ALS who flew across the country to National Advocacy Day. When he saw the number of people who had come out, it changed his whole outlook on life.

"He had felt hopeless," Wood said. "When he came, he discovered that there are a whole lot of people very interested in his welfare. Numbers mean a lot."

LeAnne Johnson, Minnesota Chapter social worker, agrees. "The number of people with ALS is small, but the toll it takes is huge," Johnson said. "Going to National Advocacy Day and seeing the number of people there with the disease gives people with ALS and their families hope, and they feel like they've gained something by speaking up."

National Advocacy Day has proved quite successful in the past, as The ALS Association has helped bring about several crowning achievements that have improved the lives of people living with ALS. In addition to the presumptive disability ruling approved by the SSA last year, ALSA and its advocates are responsible for substantial changes in Medicare practices. In December 2000, Congress voted to waive the two-year waiting period for Medicare that is normally required once a person goes on disability. People living with ALS no longer have to wait two years, many times with the disease fully progressed, to start receiving health care at a reasonable cost. With the upcoming prescription drug benefit, this will be even more important. Soon, people will not only have coverage of Rilutek®, currently the only FDA-approved drug for ALS, they also will have access to medicines that treat their symptoms.

Gibson explains the department's achievements as two-fold: First, the Public Policy Department has collaborated with ALSA's Research Department to secure more federal research funding, expanding from one institute at NIH, the National Institute of Neurological Disorders and Stroke, to eight different institutes now interested in ALS. Second, the department has expanded its focus on helping people with ALS continue to live with the disease now while ALSA researches potential therapies.

"The Medicare waiver and presumptive eligibility with the SSA are prime examples of how we can join forces to help people with ALS today while we search for a cure or treatment tomorrow," Gibson said.

Oppenheimer agrees that National Advocacy Day is an important way for people with ALS to contribute to their own quality of life. "There's not a lot that you can control with this illness," Oppenheimer said. "And this gives you a sense of power and control. We are small, and some of us are silent, but we can band together and impact legislation that affects our everyday lives."

Sen. Arlen Specter (R-Pa) greets Shelbie Oppenheimer after hearing

The ALS Association recognizes that each individual in the ALS community plays a crucial role in changing public policy, so each year at National Advocacy Day, ALSA gathers all the advocates together to celebrate the achievements and to give awards, including the Rasmussen Advocate of the Year Award. Last year, Sarah Wood was named Advocate of the Year for her hard work beginning as the Advocacy Chair at her local chapter when her husband was diagnosed with ALS. Since his death, Wood has continued to advocate on behalf of people with ALS and recently created a program at her chapter, collecting signatures for public policy concerns at Walk-related events. This program is now a nationwide campaign called "I Took the Extra Step."

"As I walked up to accept the award, I was so moved by the patients who reached out to me and thanked me for my work," Wood said. "I know what these people go through, but this really brought me face to face with why I'm doing this."

As advocates return from the trip, encouraged by their experiences on Capitol Hill, Gibson says they are exhausted, but are filled with a sense of accomplishment that no one can know until they have had the same experience.

"Advocacy Day is really an opportunity to see the hypothetical become reality," Gibson said. "In the search for a cure, it's hard to see the benchmarks as we make our progress. But when people come back from the Hill, they have this unique smile because they have seen advocacy in action and know that they have been heard. As one person with ALS speaks with one Congressional representative, each is helping to light the way to a treatment or cure for this disease."

For more information or to sign up for National ALS Advocacy Day, please call (877) 444-2572 or visit www.alsa.org.

Marilyn and Milton Safenowitz

NEW FELLOWSHIP BUILDS A PATHWAY TO HOPE

By Janet Young

Finding a cure for ALS depends on innovative ideas, new research methods, and a steady influx of young researchers entering the field of ALS research with a strong commitment to unlocking the secrets to the disease.

The Milton Safenowitz Post-Doctoral Fellowship for ALS Research, made possible through a $1 million grant from Marilyn Safenowitz and the Milton and Marilyn Safenowitz Family Foundation through ALSA's Greater New York Chapter, will provide young post-doctoral students with the unique opportunity to stand at the forefront of ALS research and partner with the best scientific minds in the quest for a cure.

The Milton Safenowitz Post-Doctoral Fellowship for ALS Research is the only ALS-specific post-doctoral fellowship program in the country. In 2003, ALSA's inaugural fellowship was awarded to Jonathon H. Lin, M.D., a recent doctoral graduate of Columbia University of New York, with support from The Lawrence and Isabel Barnett Charitable Foundation. Lawrence Barnett is a member of ALSA's National Board of Trustees and serves on several of its committees.

The fellowship program ensures that there will be a steady stream of young minds entering the field of ALS research on an annual basis. Two-year fellowships will be granted based upon a competitive review process by a committee, which includes the Chairs of ALSA's Scientific Review Committee and Cure ALS Advisory Committee, as well as ALSA's Science Director and Vice President Lucie Bruijn, Ph.D.

"Our family believes that supporting young scientists and encouraging them to bring new perspectives into the study of ALS is vital," explained Milton Safenowitz's wife Marilyn, a Trustee of the Greater New York Chapter. "If we can excite post-doctoral students and encourage them to focus their efforts on the study of ALS, we may have a better chance of understanding this devastating disease."

The Milton Safenowitz Post-Doctoral Fellowship for ALS Research is named in memory of Milton Safenowitz, who lost his battle with ALS in 1998. Born in Brooklyn, New York, he attended Brooklyn Automotive High School. Upon graduation, he took his first job with the New York Transit Authority. A few years later, he and a partner purchased their first gas station in New York in 1955.

The purchase of additional gas stations led the partners to eventually become Texaco distributors. When Texaco acquired Getty Petroleum, the two partners were offered the opportunity to purchase the Getty stations and Getty brand from Texaco. Together, Safenowitz and his partner built the Getty Petroleum Marketing Company and Getty Realty Corporation, where Safenowitz served as Executive Vice President until his retirement in 1990.

When not focusing on business, Safenowitz was dedicated to helping others in the community. "He was always extremely philanthropic, even as a young man," Marilyn Safenowitz said. "Milton understood that he had a responsibility to give back to the community. The Milton Safenowitz Post-Doctoral Fellowship for ALS Research is our family's way of honoring Milton's passion and ensuring that his legacy of giving is carried on."

Safenowitz was always very dedicated to his family, as well. His children and seven grandchildren remember a man who was humble and very caring – a man who put family above all else. "Even when he was successful, he remained low key and unpretentious," said Howard, Milton Safenowitz's son and an ALSA National Trustee. "Success never changed the person he was, a genuinely good man."

"Our family feels strongly about supporting the work of The ALS Association," Marilyn Safenowitz said. "Who is going to take care of the ALS community if not those who have been personally touched by this disease? Nothing serves as a greater tribute to Milton's life and his valiant fight with ALS than the hope that we will find a cure. The Milton Safenowitz Post-Doctoral Fellowship for ALS Research offers that hope."

ALS Research Today:

A Conversation with ALSA's Science Director

Dr. Lucie Bruijn came to The ALS Association in 2001. As Science Director and Vice President of Research, Dr. Bruijn directs The ALS Association's diverse research program, which is seeking to unravel the mysteries of ALS. Holding a bachelor's degree in pharmacy, a master's degree in neuroscience and a doctorate in biochemistry, Dr. Bruijn developed and characterized one of the mouse models of ALS. Dr. Bruijn spoke with HOPE about the state of research into ALS today, and her views about the future.

HOPE: Why are you excited about the current state of ALS research?

BRUIJN: ALS research has changed dramatically over the last ten years. There are many more investigators looking at the disease. People with a variety of expertise are coming on board, in part, because we have the tools to address many of the problems. The technology has matured, and a lot more is understood about the disease. And most importantly, we have an animal model that makes it much easier to study the disease. This is an environment where researchers are now collaborating much more extensively, and projects involve many institutions. There also is good collaboration among many of the ALS organizations. I think the spirit of working together is making much more of an impact on the research.

HOPE: How would you describe ALSA's research portfolio and its approach to fighting ALS from the scientific viewpoint?

BRUIJN: ALSA is funding a broad range of projects covering topics in ALS today. Our research portfolio encompasses many different ideas and approaches. We invite investigators to submit proposals. In addition, we proactively seek investigators for specific projects. All projects are peer-reviewed. We entice new people into the program, and we work with investigators to develop new projects. We view ALS as an open horizon for researchers. Limited initial funding for what appears to be risky ideas may blossom into full-scale projects if the start is successful. Beyond funding research, we focus on workshops and creating venues for investigators to exchange ideas. Our approach is inclusive, collaborative and innovative. ALSA believes it takes many different kinds of research programs to achieve success in finding treatments and a cure.

HOPE: How did you become interested in ALS?

BRUIJN: I'm a pharmacologist by training and my graduate studies focused on Alzheimer's disease. I always had an interest in trying to understand disease pathways, and how to find drug therapies to treat disease. That led me into both a scientific career path, and by coincidence really, into the ALS field. I came to the United States after completing my graduate studies in the United Kingdom. At that time, the SOD mouse for ALS was being developed, and it seemed like a really exciting time to be involved with ALS research. After doing my post-doctoral studies, I went into the pharmaceutical industry because I was interested to see research go from basic science into the development of therapies for disease. I led a small team of scientists developing models for diseases that could be used to test compounds. So, when I was asked to lead the ALSA science program, it seemed a logical combination of all my previous experiences both in doing basic lab research and leading teams trying to solve problems. The excitement and challenge of leading such a significant effort attracted me immediately and continues to be a rewarding enterprise.

HOPE: Describe the progress made in ALS research over the last decade?

BRUIJN: In many ways, it appears that there's been more progress over the last decade than since ALS was discovered in 1869. Before the discovery of the mutations in the SOD1 gene and the development of an animal model of ALS, it was more difficult to test various disease theories. Previously, most researchers focused solely on one cell type, the motor neuron. We've now accepted that the disease is much more complex. There are many more cells, such as the neighboring cells – astrocytes and microglia – that are responsible for and integral to how the disease occurs. Because of the ability now to mimic human ALS in a mouse model, we were able to consider what happens in the disease prior to the onset of symptoms.

When physicians see ALS in humans, the disease has already started, and they are unable to see how the disease developed prior to symptom onset. With animal models, you can study these developments over time. So, there has been an incredible increase in our ability to understand the disease. With the ability to test compounds in the ALS model of the disease and our increased understanding, there are a greater number of clinical trials now as compared to 10 years ago. With this has come a huge increase in the number of investigators and academic institutions focusing on the disease.

HOPE: Many patients and families ask, "When will we find a cure?" How do you answer them?

BRUIJN: I would do a disservice to actually give a timeframe that we don't know and we can't meet. First, we have to remember that ALS is a very complex and difficult disease. We have made huge progress in understanding how the cells of the brain work and how things network in an organism. However, ALS is a very complex network of different cells, and all these cells have to wire up exquisitely to ultimately cause muscle contraction. It's not as if we can just give an antibiotic and get rid of a bacteria. It's likely that there are many different causes of the disease. We have made remarkable progress and now have the ability to test compounds. But, we're not waiting for one outcome before we learn about the next. Many approaches are being taken in parallel, so there is no timeframe that we can give. Two years ago, we hoped that stem cells would be in the clinics this year. This hasn't happened. It's not a straightforward process, but we have a worldwide enterprise focusing on the challenges.

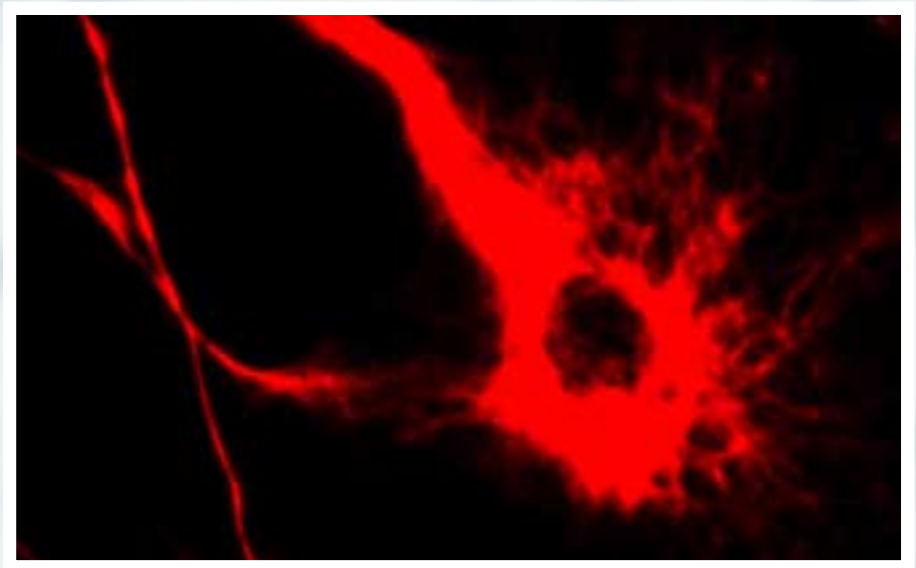
In addition, it is crucial that ALS organizations work together, setting aside competitive differences, in the effort to find treatments, help patients, and ultimately find a cure.

HOPE: What are the most important discoveries in ALS over the last 10 years?

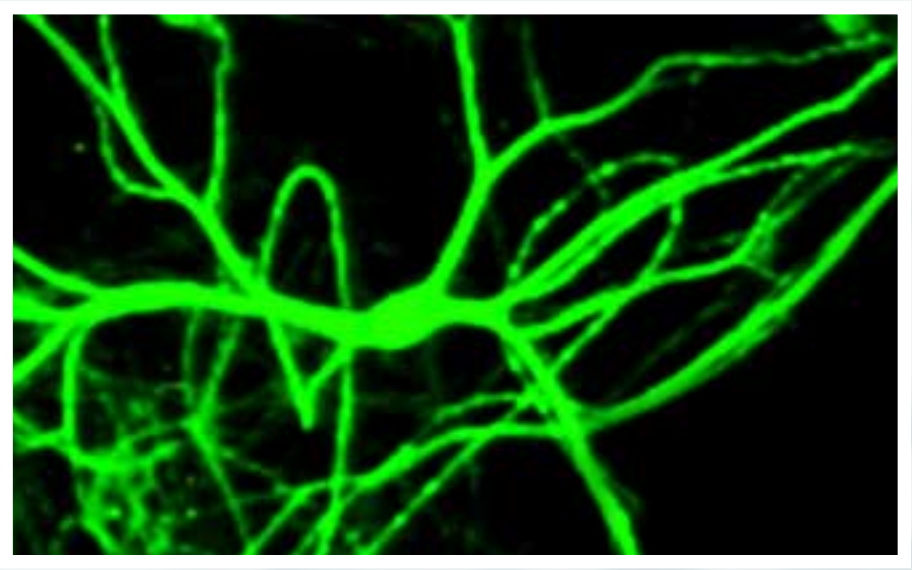
BRUIJN: The first and most important breakthrough was the discovery of the mutations in the SOD1 gene, which accounts for 20 percent of familial ALS. This led to the development of a model of human ALS in animals that initiated investigation into how the disease operates. Initially, it seemed we would solve the riddle of ALS very quickly; however, we found it to be very challenging. Even though we know how this gene functions, we learned that the mutation is an acquisition of a toxic property. We discovered that the disease is caused by a function that the gene has gained, rather than the loss of its normal function. We still are unclear about what that gain of function is. The second big discovery was the fact there are multiple cell types involved in ALS. It's not only the motor neurons, but also the supporting cells surrounding the neuron. This led us to think more carefully about the muscle itself as an important target. So we now think about the disease in much a broader context. A third important discovery is that the disease is likely to have multiple causes and/or triggers. In addition, it is likely that there is interplay between genetic and environmental factors in ALS.

HOPE: Where do you see the most exciting and promising research?

BRUIJN: There are so many unknowns, and the answer could come from an obscure area. ALSA's research program aims to fund efforts in many different areas of the disease. I believe many clues lie in understanding more about the genetics of the disease. We only have the very beginnings of the puzzle by having found the SOD1 gene mutations, which accounts for 20% of familial ALS, so there's 80% that is still unknown. If we find more problem genes, we might be able to put these all into a pathway and understand how the disease works. And, of course, any one of these genes could provide a new drug target. Interest continues in the various approaches to therapy. Our biggest wish would be for a drug to come along that's similar to an aspirin. You pop a pill and your condition would be



Astrocyte, one type of cell surrounding the motor neuron



Motor Neuron

improved. But in reality, we've got to keep an open mind. Currently, the only FDA approved drug we have is Riluzole (Rilutek®). Stem cell biology is a very promising area. Stem cell research can be viewed as a different means of therapy. It could be utilized to replace cells that are unhealthy, or it might be a means to bring compounds to the unhealthy cells by putting therapeutic compounds in these stem cells. These cells would migrate to a damaged area and act as a sort of a "mini pump" to provide medication that in many cases cannot easily reach the proper cells. Also, gene therapy is becoming a much more exciting, mature field. By its very nature, gene therapy has always been a challenge. It involves delivering genes by a viral vector or carrier, and of course, the virus is no longer infectious. However, there are obviously concerns about administering viral vectors for any discipline, including ALS. There are currently clinical trials in other diseases using these viral vectors, and there's one in the planning stages for ALS. Gene therapy is very important because it allows substances such as growth factors to reach dying cells. These growth factors, unfortunately, cannot be administered by tablet. There have been unsuccessful clinical trials in using growth factors like GDNF and BDNF for ALS. Most investigators believe that it's probably because these factors are not getting to the appropriate area. Using gene therapy, you're able to target more effectively and take the product that you need right to the damaged area. Another promising development is the increasing involvement of academia in the development of assays and screening drugs. A key to success is developing the best assay system, which is basically a model of ALS in a dish that mimics one aspect of the disease. Here, you can use compounds to test how to modulate that particular disease mechanism. With the assay system, you can study many different drugs in a very short space of time. These drugs can then go into an animal system, where you can test which of the compounds would be valuable to take to clinical trial.

HOPE: Are we moving closer to clinical trials and finding new drugs to treat ALS?

BRUIJN: There is an increase in the number of clinical trials. However, are we finding the drug that's going to make a huge difference? We still have many challenges. Not every person manifests the disease in the same way. The time of onset and the speed of progression are variable. The duration is very variable. Importantly, we are able to bring more drugs to the clinic because of 10 to 15 years of solid research focusing on disease mechanisms that has gone on to this point and because we have different mechanisms to test.

We also have compounds that have come from other neurodegenerative diseases that we can test on ALS. I believe an important way to improve clinical trials would be to identify good diagnostic biomarkers.

HOPE: What role do you think the environment plays in ALS?

BRUIJN: The environment is likely to play a role, but I believe the disease is caused by an interaction between environmental factors and a person's own genetic make up, explaining why one person may be more vulnerable to the disease than another. It is difficult to pinpoint what genes and environmental factors are involved, but more emphasis is being placed in this area of research.

HOPE: Is ALSA's research relevant for those who have the disease now?

BRUIJN: Absolutely. ALSA's program covers all aspects of ALS. We fund areas of very basic research because it's through the understanding at the cellular level that we can drive therapies into the clinic. At the same time, we have developed model systems for ALS to test therapies with the information we already know about potential ways in which the disease operates. ALSA is funding a diverse research portfolio addressing projects that will impact patients now, as well as making sure we fill the pipeline for the future.

To read more of the interview with Dr. Bruijn, please visit www.alsa.org/research.

Larry and Isabel Barnett

A Portrait of Generosity and Involvement

It was 26 years ago when a close friend called Larry Barnett and shared the news that his wife had been diagnosed with amyotrophic lateral sclerosis (ALS). "I asked him what ALS was," Barnett remembered. "And, I asked how I could help."

Barnett was not alone in his limited knowledge of ALS. Although more than 30,000 Americans have ALS at any given time, few people know that this devastating disease has no known cause and no known cure. Employing his experience in fundraising, Barnett joined the effort to help lead the search for a cure for ALS.

Because of his enthusiasm and leadership ability, Barnett was elected Chairman of the ALS Society of America (ALSSOA) in 1981. When ALSSOA merged with the National ALS Foundation to form The ALS Association (ALSA) in 1985, Barnett was named the first Chairman. Barnett has remained steadfast in his commitment to ALSA ever since, and even at the age of 90, continues to devote a tremendous amount of his time, talents and resources to finding the cause and a cure for ALS.

"I guess
I am considered
the grandfather
of The ALS Association,"
Barnett shared.
"That's a distinction
I'm very proud of."

Barnett serves on ALSA's Board of Trustees, as well as its Research, Board Operations and Development Committees. He is also Honorary Chair of ALSA's Lou Gehrig Challenge: Cure ALS Research Campaign, the most ambitious and promising ALS–specific research program ever launched, aimed at finding treatments and a cure for ALS.

"It is my personal mission to stamp out ALS," said Barnett, who has underwritten numerous research grants. One research project he supported eventually isolated the SOD1 gene that causes some forms of ALS. When he received news of this discovery, Barnett was elated. "This breakthrough brings us one step closer to finding the cause for the disease," Barnett said.

To ensure a steady stream of young minds aggressively study ALS, Barnett provided funding for ALSA's inaugural Post-Doctoral Fellowship. The Lawrence and Isabel Barnett Post-Doctoral Fellowship was awarded in 2003 to Jonathon Lin, M.D., Ph.D., a recent graduate of Columbia University.

Barnett is not alone in his commitment to ALSA. His wife of 50 years, Isabel, shares his devotion to The ALS Association and numerous other charitable causes, including supporting research into the prevention of blindness, Alzheimer's disease, Parkinson's disease, and arthritis. Barnett is a Trustee for the Eisenhower and Annenberg Medical Centers, and Isabel is Vice Chair on the Board of the McCallum Theater in Palm Springs.

Larry Barnett serves on the National Campaign Executive Committee at his alma mater, Ohio State University. The Barnetts have established two funds that support the Arts Policy and Administration Program in the University's College of the Arts. The Lawrence and Isabel Barnett Distinguished Visiting Professor Fund supports an annual Barnett lecture series and biennial Barnett Arts and Public Policy Symposium. In addition, the Lawrence and Isabel Barnett Fellowship Fund provides tuition, fees and an annual stipend for promising arts policy and administration students.

Barnett also helped one of the largest psychiatric hospitals in the country, Hillside Hospital in New York City, and supported the Adoption Society of Westchester in White Plains, New York.

"I've always felt like I needed to help humanity as much as I can. And we are fortunate enough to be able to give back to the community and make a difference," Barnett said. "Even as a child, I wanted to help others."

Larry Barnett was raised in Orrville, Ohio, a small town of 4,000 people. The youngest of four children, he took violin lessons from the only music teacher in town. Barnett attended Ohio State as a business major in the 1930s and quickly found that his talent as a violinist could fund college expenses. He paid his way through school leading his band, "Larry Barnett and his Orchestra."

Eager to pursue a career in show business, Barnett left college one quarter before graduation and took a job in the talent department of Columbia Broadcasting System (CBS). When Music Corporation of America (MCA) bought CBS's talent agency, Barnett went with MCA, where he became President and served on the Board of

Directors. Barnett also held leadership positions with General Artists Corporation, Chris-Craft Industries and United Television, Inc. In addition, he was associated with Piper Aircraft Corporation and Warner Communications, Inc.

Barnett met his wife, Isabel, when he was working with MCA, at that time the largest theatrical agency in the United States. Isabel Bigley was playing the lead in the London production of Oklahoma. She would later win the Tony Award for her portrayal of the lead in Guys and Dolls. Isabel signed with the MCA label and four years later, they were married.

The Barnetts have 6 children, 16 grandchildren and 4 great grandchildren. "Our family is our greatest accomplishment and the thing we are most proud of," Isabel said. "We have a blessed life," Larry added.

Always desiring to complete his undergraduate studies, Barnett contacted Ohio State University in 1988 after retirement and returned to school to earn his Bachelor's degree in Business.

"It was a very happy moment for me," said Barnett. "I'd wanted to go to night school and get my degree when I was young, but never had the time. I'd finished everything in life, and it always bothered me that I never finished college." Barnett was also honored with a Doctorate in Fine Arts from Ohio State.

Today, the Barnetts devote their time to helping others. "I want to be able to look back at my life and say that I've done something for other people – that my life wasn't a selfish life," Barnett said. The Barnetts have instilled the same sense of giving in their children, who are carrying on the family legacy of helping others.

Barnett's commitment to the fight against ALS has not gone unnoticed. The ALS Association presented him with its Donald W. Mulder Award for Leadership, Dedication and Achievement in 1993, and he was the first recipient of the Jacob Javits Lifetime Achievement Award two years later.

This past November, the ALSA Board of Trustees launched the Larry Barnett 90th Birthday Challenge in recognition of Barnett's unwavering commitment to ALSA. To date, more than $1 million has been raised in Barnett's honor in support of ALSA's mission to find a cure for and improve living with ALS.

"I have had the pleasure of serving with Larry Barnett since ALSA was founded, and I have witnessed his unwavering commitment to make a difference in this world through his leadership and philanthropic efforts on behalf of the ALS community," Robert Abendroth, ALSA National Trustee and Chair of ALSA's Research Committee, said. "This campaign not only celebrates Larry's milestone 90th birthday, it serves to honor all he has done for ALSA. Larry was there when ALSA was formed, and so much of what ALSA has achieved is due to the support he has given over the years."

Said Barnett, "ALS causes have really been my heart." His commitment is often renewed when he meets someone with the disease.

"Every patient makes an impression on you. When you meet a person with ALS, you keep asking yourself, 'What can I do to help this person?' It reinforces that we need to act quickly to find the causes and a cure for this disease." His faith remains unwavering.

JY

"We're making progress
in research.
Sooner or later, we will
find the answer,"
Barnett said.
"My desire always was
to find a cause
and a cure for ALS.
And, this is my heart,
and my desire,
to accomplish something
in this world."

"Everyone took turns pulling me in the wagon, and it occurred to me later that this was the same approach that sees me through every day: my family and friends pitch in, doing whatever they can so no one is exhausted having to do it all. And I just sit back enjoying the scenery."

Michael Jack

COMMUNITIES ACROSS THE NATION WALK TO D'FEET ALS®

Purple chenille pillows filled the Amish-made wagon, in which Michael Jack was stretched out feeling the cool autumn air rushing past him. Members of the team walking in his honor, the JackALS, pulled him along in the ALSA Washington, D.C., Maryland and Virginia Chapter's first ever Walk to D'Feet ALS in 2000.

"I remember it was a crisp morning – decidedly cool but radiantly sunny – with vivid fall colors," Jack said. "My team is comprised of folks from many chapters of my life, including several who made special trips for the occasion. Each one's presence made me feel a bit stronger. People had asked me what they could do, and suddenly there was this concrete opportunity to support my cause, not only with their financial resources, but also with their presence. And now it's a tradition."

Each year, The ALS Association's (ALSA) national network of chapters holds multiple Walks as part of Walk to D'Feet ALS, ALSA's signature event held in cities across the country to promote public awareness about ALS and raise funds for ALS research and local patient and family services. Each Walk, held primarily during the spring and fall months, is based on participation of teams walking in honor or in memory of a loved one with ALS. Each team picks a captain who initiates a letter writing campaign to family and friends asking for donations.

Pat Freiberg, the newly appointed Director, National Signature Event for ALSA, has organized the DC/MD/VA Chapter's Walks from the start, and she points out that the Walk to D'Feet ALS is a unique event because of its noncompetitive nature.

"It's a wonderful community event where people come together with joy and passion for a common cause," Freiberg said. "Participants don't break away from the team; everyone walks together."

Dorine Gordon, a member of ALSA's Board of Trustees, chair of the Community Services Committee and president of the Greater New York Chapter Board, knows family members who have flown from across the country to participate in the Walks and used the opportunity to have a family reunion as well. Families often attend the Walk in the morning, spend the afternoon together and go out to dinner in the evening.

In addition to providing families and friends with the opportunity to make a financial impact and support their loved ones, the Walk program has become a national signature event for The ALS Association and a significant source of funding. Last year, chapters held Walks in 110 cities across the nation, with approximately 100,000 participants raising more than $7 million. This year, the goal is to raise $8 million through the 140 Walks that will take place in 120 cities nationwide.

"The Walks work no matter how large or small the chapter's resources," Gordon said. "It's a program in which all chapters can be successful, and it just keeps growing."

Last year, 100 percent of ALSA's 39 chapters held at least one Walk in their communities, including a new chapter-in-organization formed in Iowa that had started planning their Walk prior to officially joining ALSA.

"The great thing about holding a Walk is that it doesn't have to have a lot of expenses, but it can bring in a lot of money, so smaller chapters can still be successful," said Roger Gould, Iowa Chapter Board president.

Local Iowa resident Ellen Janke had been looking into organizing a walk in honor of her sorority sister, Sharon Stahly, when she came across the Walk to D'Feet ALS on The ALS Association's national web site. After some coordination with the National Office, Janke was referred to Gould, who was in the process of forming The ALS Association Iowa Chapter.

Michael Jack and his Walk team, the JackALS

By the time Iowa held its first Walk to D'Feet ALS, it was officially part of ALSA and had rallied together 133 participants, raising more than $18,000. Janke's team of sorority sisters from Beta Sigma Phi totaled a dozen, raising nearly $1500.

"We felt compelled to do something beyond our routine fundraising to express our concern for Sharon and others in our community who are living with ALS," Janke said. "The Walk to D'Feet ALS provided us with just the right opportunity to help. It not only helped us raise funds, it helped raise our own awareness of the number of people in our community that are living with this disease."

With a program that continues to grow nationwide, The ALS Association has established the position of Director, National Signature Event, to direct the Walk efforts. Experienced in coordinating the Walks for the chapter that has raised the most Walk to D'Feet ALS funds, Freiberg is now a resource for chapters of all sizes and experience levels holding Walks.

"I have seen the impact of the local community on my chapter's events," Freiberg said. "I am excited to see the success of the national ALS community working together to pool their creative resources for each local event. I'm continually amazed by the unique concepts that each chapter has created."

Sarah Wood, a member of ALSA's National Board of Trustees and Western Pennsylvania Chapter Board president, created the idea of weaving public policy efforts into Walk-related activities, such as gathering signatures for bills that The ALS Association's Advocacy Department is supporting. This year, ALSA will launch a nationwide campaign called, "I Took the Extra Step," encouraging each Walk participant to sign a letter to a member of Congress, highlighting a legislative priority for that year.

Gordon is optimistic about the "I Took the Extra Step" campaign, expressing support for its ability to not only help raise awareness of the disease in Washington, but to raise awareness around the country that The ALS Association is the only ALS organization in Washington, D.C. advocating full-time for people living with the disease.

"With the success of the Walk to D'Feet ALS program, we are now looking to expand it by integrating other ALSA programs," Gordon said. "The 'I Took the Extra Step' campaign will highlight just one area in which The ALS Association continues to fight full-time on behalf of people living with ALS."

Michael Jack agrees that the Walk program is pivotal in raising awareness about the disease. "It's so rare that you get people from the ALS community together that you have to make the most of it when you do. There really is strength in numbers," Jack said.

Sharon Stahly's team: behind Sharon left to right are Carolyn Klaus, Eileen Muff, Ellen Janke, Pam Hinderaker and Joan Senne; far back are Laani Hill and Joyce Vegge

By pooling successful programs like "I Took the Extra Step," Freiberg hopes not only to raise awareness of all of ALSA's programs, but also to increase the impact of the Walks on the people that participate.

Freiberg shared a touching moment at one of the Walks she attended, describing a woman with ALS who could no longer speak and her husband, both in wheelchairs, who suddenly stood up from the wheelchairs and started dancing for a brief moment as a jazz band played.

"They couldn't walk," Freiberg noted, "but that didn't stop them from dancing. And that's what this is all about: giving people the opportunity to celebrate their time together and to realize that they are not alone, and that they are making a difference just by being part of the Walk to D'Feet ALS."

KT

For more information or to organize a team for Walk to D'Feet ALS, visit http://www.alsa.org. A list of upcoming Walks can be found at http://www.alsa.org/walk/where_participate.html.

Having ALS Doesn't Mean You Stop Living

Andrew Fleeson may be losing muscle control from ALS, but he has yet to lose his sense of humor or his zest for life.

"I learned long ago that when you laugh, the world laughs with you, cry, and you're on your own," Fleeson said. "When I wake up in the mornings, I think to myself, 'Well, old Nick, I know you've got me in your sights, but today's not your day. Keep my seat warm, though.'"

A citizen of the United Kingdom, Fleeson was diagnosed with ALS in March 1983. A fan of the late David Niven who died of ALS, Fleeson was aware of the path the disease takes, and he feared he wouldn't live to see his 40th birthday or his children reach adulthood. Fleeson was devastated, but one day decided on a new outlook.

"I realized that I'm not dead yet, and there are still a ton of things to do, so let's get on with it," Fleeson said.

Fleeson served for nearly a decade on the Board of the United Kingdom's Motor Neurone Disease Association (the UK equivalent to The ALS Association), and six of those years as honorary treasurer. Although Fleeson had received immense support from most of his family, they lived far apart, and after he and his wife divorced, he moved to Arizona to start a new life.

"When I stepped off the plane, I didn't know a soul in Arizona," Fleeson said. "That was four years ago, and I now have a wonderful new "family" of friends and neighbors who help me enjoy my life to the fullest."

In May 2003, Fleeson joined The ALS Association's Board of Trustees, now serving on the Communications, Community Services, Finance, Operations & Administration, Patient Services and Research committees.

"At first I didn't think I had too much to offer The ALS Association, especially since I am not an American," Fleeson said. "But after working with them for a few months, I was so moved by the work they were doing that I accepted their invitation to join the Board."

The former sales and marketing director for a computer systems company in the UK, Fleeson now struggles with his new life, striving daily to challenge himself. One way Fleeson encourages himself is by learning something new every day, scouring the Internet for news and media web sites.

"The challenge that frustrates me the most is boredom," Fleeson admitted. "I can't bear not being intellectually engaged for any length of time. And some of the articles online are just hilarious."

Fleeson is also encouraged by advances in research of therapies that have the potential to slow dramatically or even halt the progress of ALS. In addition, he believes that research is on its way to discovering predictive technologies that will be able to identify individuals who have a high risk of developing ALS so that they can receive treatments that will prevent the disease from becoming active.

"The sheer scale of the research being carried out worldwide by top class researchers and their achievements to date give me tremendous hope for the future, for myself and for my fellow travellers on the ALS journey," Fleeson said.

Fleeson adds that his global perspective gives him the opportunity to encourage The ALS Association to seek out international research on this disease.

"I always try to remind my fellow Board members that ALS is not just an American disease, it is truly worldwide," Fleeson said. "We can't be afraid to look up and look over the garden wall."

Fleeson is also making an effort to keep everyone living with ALS, as well as their loved ones and supporters, optimistic about the difference that each individual can make in the fight against ALS.

"I like to remind people that a diagnosis of ALS might be a sentence of death, but it is certainly not a sentence to stop living," Fleeson said. "I know progress in our fight against this cruel disease may seem frustratingly slow, but if we keep faith and pull together, we will win."

Now at the age of 59, Andrew Fleeson has been living with ALS for more than 20 years, and he added, "And I'm still getting on with it."

KT

"I realized that I'm not dead yet, and there are still a ton of things to do, so let's get on with it,"

LEGACY OF

HOPE

HOW WILL WE BE REMEMBERED?

By John G. Watts

George and I said goodbye for the last time in October. We were together with our wives at a restaurant in Interlaken, Switzerland. George, in an advanced stage of ALS, was struggling with his dinner. The next morning my wife and I drove George and his wife to their home in Lausanne. He sat in the front seat with me, reflecting on his life and its meaning as he realized the time was short. His reflection included how he would serve his community with the life he had left to live.

George and I had known one another for 30 years, having become acquainted on our first day of graduate school. I knew he was someone special, unique and refreshingly unconventional. He had a flare for living life out of the ordinary rut. His zeal for living affected everyone around him. He had a beautiful sense of justice and would tackle any project when it came to achieving something he believed in very deeply. His resolute character often transcended established protocol—I have great admiration for his courage. George was also brilliant. It is particularly meaningful to me that he retained a clear, sharp mind throughout his fight against ALS. Two months after George and I had dinner in Interlaken, he lost his battle with ALS.

All of us could benefit from the kind of reflection George engaged in on our trip back to Lausanne. The question—how can we make a difference in our world with the time we have left to live?

Charlie, a seriously ill eight-year-old boy from Philadelphia, devoted his young life to finding ways of feeding the homeless in the inner city until he died at the age of 11. Charlie left an inspiring legacy in the City of Brotherly Love, a legacy by which he will long be remembered. George, too, will long be remembered because he touched so many lives.

In a survey of older people, the number one aspiration was to be remembered for living a life by which they could be remembered. It seems that nearly every week we read a story of sacrifice by women and men who leave a legacy by providing a gift in their will or trust to endow educational scholarships, provide for the needy, or help to eradicate a dreadful disease like ALS.

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