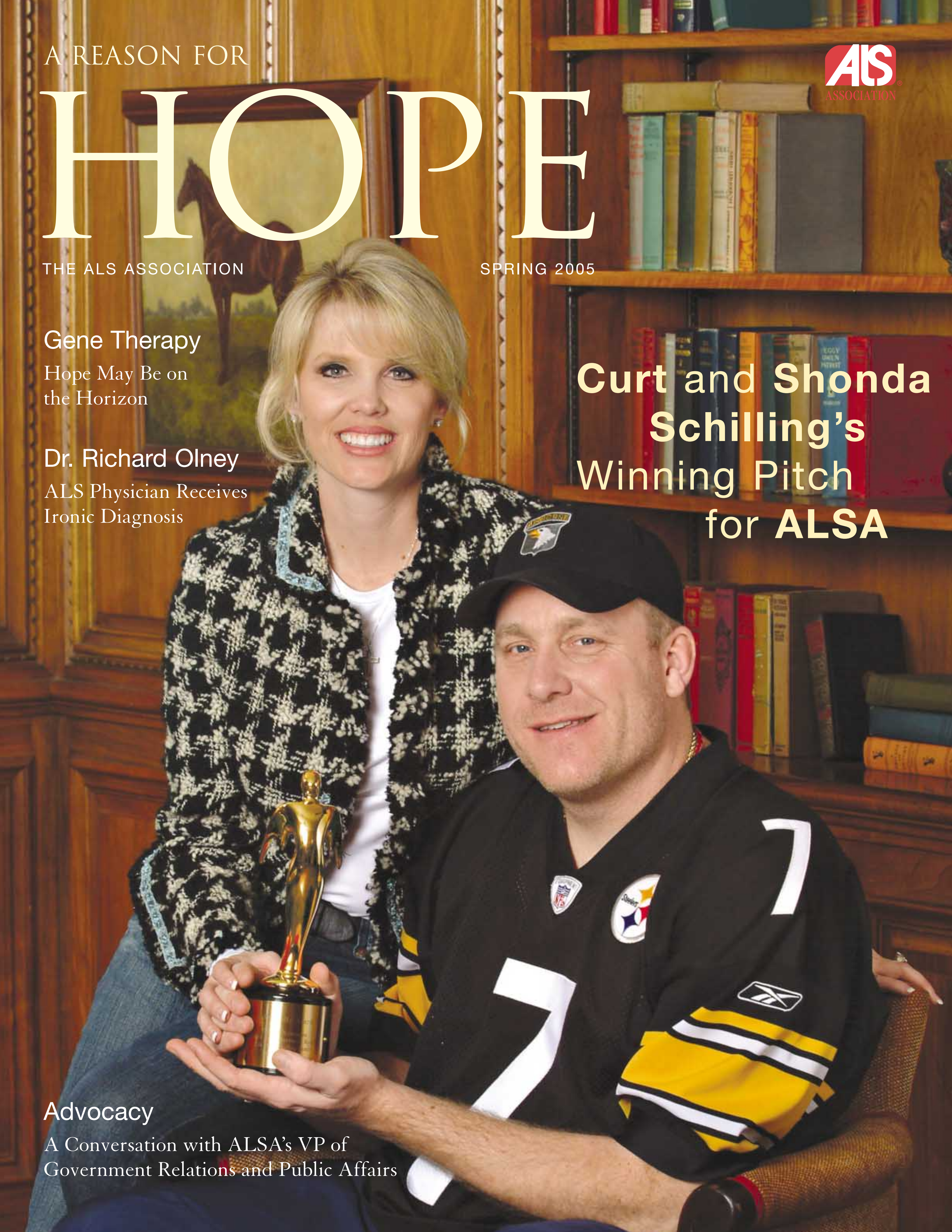
A REASON FOR

HOPE

THE ALS ASSOCIATION
SPRING 2005



Gene Therapy

Hope May Be on the Horizon

Dr. Richard Olney

ALS Physician Receives Ironic Diagnosis

Curt and Shonda Schilling's Winning Pitch for ALSA

Advocacy

A Conversation with ALSA's VP of Government Relations and Public Affairs

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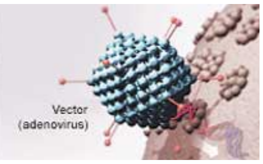


ABOUT THIS ISSUE… A Reason for HOPE magazine casts a revealing light on subjects foremost in the minds of people who are living with ALS, their families, loved ones and caregivers. This issue focuses on awareness and advocacy.

Our cover story features World Series-winning pitcher Curt Schilling and his wife, Shonda, who dedicate much of their time and energy working with ALSA in the fight against ALS. They enlist their notoriety to help raise money to fund research and patient care efforts, and they work tirelessly to increase public and government awareness about Lou Gehrig's disease.

Neurologist and ALS researcher Richard Olney, M.D., shares his true-life story about a physician who spends most of his professional life treating ALS patients and searching for a cure. In a stroke of tragic irony like a Hollywood screenplay, Dr. Olney received a diagnosis of ALS that dramatically altered his battle against the disease.

In an interview with HOPE, Steve Gibson, vice president of government relations and public affairs, discusses The Association's advocacy effort and the pivotal role ALSA's Advocacy Office in Washington, D.C., plays in fostering legislation in support of people with ALS and in encouraging increased research funding.

HOPE visited with Mary Ann Wilde, who lost her husband, Harold, to ALS several years ago, yet she continues to raise funds and to support the mission of ALSA to provide services to people with ALS and find treatments and a cure.

HOPE magazine is designed to be informative and useful. As always, we invite your comments and suggestions regarding the publication. HOPE is available on ALSA'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
Editor & Director
Communications

On the cover: Pictured on the cover are Curt and Shonda Schilling with the Telly Award given for the 2004 ALSA television public service announcement in which they appeared. The photograph was provided by Mary Knopp of Randall Photography.

THE ALS ASSOCIATION SPRING 2005

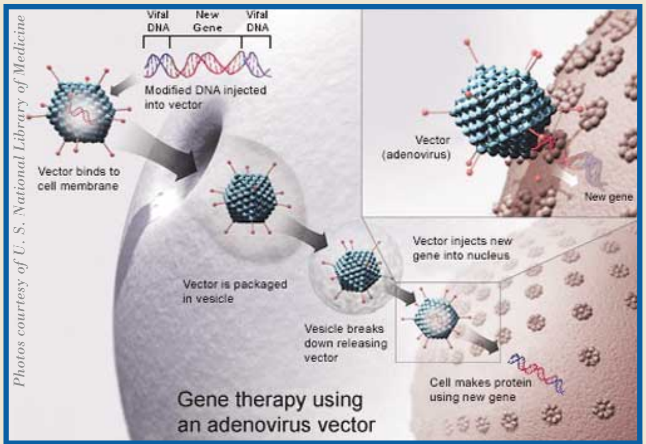
GENE THERAPY:
The Right Time and Place for ALS

by Roberta Friedman, Ph.D.

Gene therapy may be able to help nerve cells damaged by the disease process of ALS by providing a steady supply of helpful protein to the right place. The right time to treat is as early in ALS progression as possible. Most patients are diagnosed when they have lost as many as 50% of their motor neurons, but findings in animal models suggest there may still be a benefit to begin gene therapy at this time.

> **"Researchers have ways to change a virus so it is rendered harmless, but able to deliver gene cargoes."**

With the first clinical trial of a gene therapy for ALS about to begin, it is timely to look at the promise of this approach. Gene therapy can replace a single defective gene. Or, it can be a means to produce a therapeutic protein at a place that drugs cannot normally access. In most cases of ALS, the genetic errors are not yet known, but simply supplying an appropriate protein with gene therapy may salvage dying cells.



Photos courtesy of U. S. National Library of Medicine

Viral vector bearing a therapeutic gene enters a cell, and delivers its cargo to the nucleus, allowing the cell to produce the protein as instructed.

Trophic Factors and ALS

Researchers suspect that ALS affects the proteins called trophic factors that normally aid in the maintenance and metabolic needs of nerve cells. A growing body of basic research in models of ALS shows that trophic factors can help.

Thus far, human trials of trophic factors have failed. Investigators speculate that the agents have trouble reaching the crucial target tissues; namely, the spinal cord and brain.

Trophic factors tend to have short lives within the body, so they need to be continually produced. Meanwhile, a special barrier protects the nervous system from toxins and from metabolic fluctuations, and this blood brain barrier often halts compounds intended as therapeutics as well. Scientists plan to insert a gene coding for production of the trophic factors to provide on-site help for ailing motor neurons.

Ferries for Gene Therapy

Genes are not normally able to enter cells. To place a working gene inside a living animal or patient, scientists insert that gene into a vector, which is simply a carrier to get past the cell's barriers. Viruses, essentially bits of genetic material, evolved to enter cells and live there–often producing disease as a byproduct. Researchers have ways to change a virus so it is rendered harmless, but able to deliver gene cargoes. These engineered, viral vectors become the key to successful gene therapy.

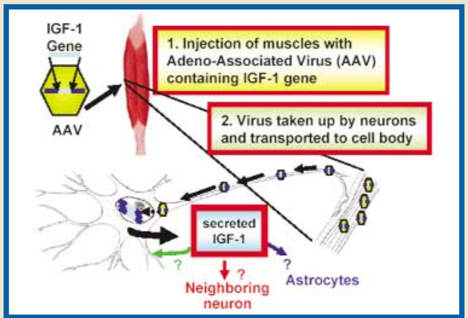
Motor Neurons Key in ALS

Scientists can take advantage of special properties of nerve cells when designing ALS gene therapy. All neurons transport materials back from their thread-like endings to re-supply the cell body, but motor neurons especially depend on this task. After all, the motor neuron may reach a meter or more to its target muscle. Capitalizing on the transport skills of motor neurons, scientists postulate that wasting muscles in ALS might be injected with vectors bearing genes for trophic factors. Through transport back up the nerve endings, trophic factors could rescue the motor neurons trying to survive inside the spinal cord. Initial data shows this indeed works in animal models.

Importantly, scientists must design into any gene therapy a way to switch off production of proteins by the introduced gene in case undesired effects appear.

IGF1: A Prime Gene Therapy Candidate for ALS

A University of Michigan team led by ALSA-funded investigator Eva Feldman performed much of the initial research on the insulin-like growth factor (IGF1).



Viral delivery of neurotrophins to motor neurons slows ALS-like disease in an SOD1 mutant model, presumably by forcing the local production by motor neurons within the spinal cord.

Scientists at the Salk Institute and at Johns Hopkins published promising results, which showed extended lifespan of mutant SOD1 mice after viral delivery of IGF-1, even when introduced at time of disease onset. This has prompted the first gene therapy trial for ALS patients.

> **"…promising results… showed extended lifespan of mutant SOD1 mice after viral delivery of IGF-1."**

For the Future

Other trophic factors are proving useful in models of ALS. Both IGF1 and glial derived neurotrophic factor (GDNF) have increased survival in ALS mice. Peter Carmeliet at the Flanders Interuniversity in Belgium, first recognized the potential role of vascular endothelial growth factor (VEGF) in ALS. Scientists working with VEGF at Oxford BioMedica have now achieved significantly increased survival in mice modeling ALS treated at disease onset with muscle injections of a VEGF gene carried by a viral vector. Discussions are underway to plan clinical testing of this VEGF gene therapy.

For further information on the clinical trial of IGF1 gene therapy, see http://www.alsa.org/news/article.cfm.

The Schillings Pitch to Strike Out ALS

By Gary Wosk

It was a sight to behold: enthusiastic ALS patients waiting in their wheelchairs to meet Boston Red Sox pitcher Curt Schilling and his wife, Shonda, at the Wrigley Mansion in Phoenix, Ariz. Together, they comprise a super fundraiser team that has raised $5 million since 1992 for The ALS Association in the fight against ALS.


Photos by Mary Knopp

Curt and Shonda address guests during the party in Arizona

At the holiday party, sponsored by ALSA's Arizona Chapter, Curt and Shonda visit tables in the Veranda Room, where the dozens of people with ALS share stories, nibble on appetizers and enjoy a majestic view of the city glimpsed through picture windows from atop their hilltop perch.

“Their tireless devotion and commitment to spreading the word and helping raise funds is quite without parallel,” said Andrew Fleeson, an ALS patient and member of ALSA's National Board of Trustees, among the first persons greeted by Curt.

> “We're going to keep fighting until we can have a victory celebration.”

“My impression of Curt and Shonda is that they are very down to earth people,” said Betty Lundberg, an ALS patient for 33 years who sits at the same table. “They're very involved with ALS and have made the entire country aware of the disease.”

Moments later, the Schillings step up to the podium. Shonda reminisces about the marathon she ran in several days earlier, crediting people with ALS for inspiring her to finish the race. Curt then gets down to the basics, hammering home themes that rally the group.

“Shonda and I want to let you know that nothing has changed from our standpoint,” said Curt. “We're going to keep pushing; we're going to keep fighting until we can have a victory celebration. The urgency on our end is never going to let up until we have a cure.”

Following an appreciative round of applause, the Schillings move into an adjoining, plushly decorated reception room, where for three nonstop hours, they visit with approximately 80 of their friends who are battling ALS. They chitchatted, one-on-one, at a get together that feels more like a family reunion, because they had met their guests at past functions. The Schillings stay in contact with many of these friends throughout the year by e-mail and letters.

It was common to hear the guests express their gratitude to the Schillings for their continued support of ALSA and participation in such successful fundraisers as Curt's Pitch, Covering all the Bases, three golf tournaments and a Harley Davidson motorcycle auction. In addition, Shonda was the driving force behind the ALSA Arizona Chapter's first three annual “Say It With Flowers” luncheons, a fundraiser she is helping spearhead this year for ALSA's Massachusetts Chapter. The Schillings are quick to share their admiration for the courage these people display each day as they live with this disease, also known as Lou Gehrig's disease.

With 2-year-old towhead son Garrison nearby, Curt and Shonda visited with the guests and consoled, patted hands, offered big hugs, laughed and cried. This is a scene replicated throughout the year in other cities in which Curt has played Major League Baseball, including that of his current team, the World Champion Boston Red Sox.

“We've been fortunate enough to build relationships with a lot of these people,” said Curt, who was recognized by Sporting News as the “No. 1 Good Guy” for his and Shonda's involvement with ALSA and SHADE Foundation of America, a non-profit skin cancer awareness organization Shonda started after undergoing surgeries for malignant melanoma.

“The number one highlight for Shonda and I has been the relationships we've developed with the people who have ALS and their families,” shared Curt in an intimate moment. “It is the awareness of these relationships, which in turn, I take with me when I go out to the mound, knowing that these people are living and breathing with every pitch I throw. That is pretty neat.”

Curt gives a warm greeting to Muiris Foley

Shonda added, “I know that every five days there are ALS patients across the country that are flipping channels to find the score of the games, knowing that he is pitching for them. And that means a lot.” In 2001, Shonda received ALSA’s prestigious Lawrence A. Rand Prize for her exemplary commitment to the fight against ALS.

Over the years, the Schillings’ actions on behalf of ALSA have extended far beyond highly visible fundraisers. They also have helped significantly to increase awareness of this disease throughout the world.

When Curt was placed on the disabled list by the Arizona Diamondbacks in June 2003, he decided to spend his down time during Lou Gehrig’s 100th birthday celebration by giving interviews about ALS to radio stations across the country. Last year, the entire Schilling family, including Gehrig, 9, Grant, 5, Gabriella, 7 and Garrison, 2, filmed an ALSA public service announcement, “Lighting the Way for a Treatment and Cure,” which won the 25th annual Telly Award, recognizing excellence in commercials and programs in an international competition. Then, in January, Curt autographed official World Series baseballs for each ALSA chapter. The baseballs can potentially raise hundreds of thousands of dollars at raffles.

The Schillings emphasize that building ALS awareness is a 24/7 commitment on their part. When he pitched in game two of the World Series last fall, about an hour before taking the mound, Curt decided to write the letters “K ALS” on his right shoe for millions of TV viewers to see. On a baseball score card, “K” stands for strike out.

Shonda Schilling during ALSA’s Candlelight Vigil in Washington, D.C.

Photo by Brita Meng Outzen, Boston Red Sox

Curt Schilling played a major role in Boston Red Sox World Series Championship season

“It was kind of a spur of the moment thing,” said Curt. “I thought about it when I was putting my shoes on. I remembered how people had talked about my shoe and bloody sock from game six of the American League Championship Series. It dawned on me that the cameras were going to be all over my shoe again.”

> “It dawned on me that the cameras were going to be all over my shoe again.”

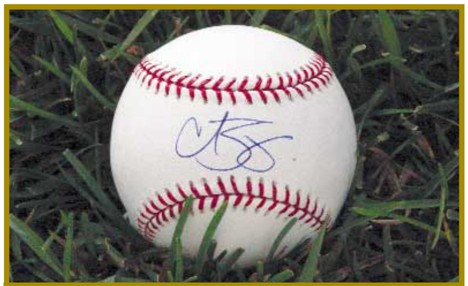
Though the baseball season can put a crimp into his hands-on involvement with ALSA causes, Curt is always in-the-know about the latest developments as a result of keeping in contact with Shonda, even when he is on a road trip. Last May, Shonda called Curt to update him on ALSA’s National Advocacy Day and Public Policy Conference, which she attended in Washington, D.C. She described to him what it was like addressing thousands of ALS patients during a candlelight vigil on the steps of the Jefferson Memorial. “To be able to go out there and see the faces of all of the people,” Shonda said, remembering the emotion of that moment. “It was very moving.”

The Schillings decided to become involved in the fight against ALS in 1992 when Curt was traded by the Houston Astros to the Philadelphia Phillies. Ellyn Phillips, president of ALSA’s Philadelphia Chapter and a member of ALSA’s National Board of Trustees, introduced Curt to ALS patient Dick Bergeron at a meeting new players were invited to attend because the chapter was the team’s official charity. After the meeting, Phillips recalled that Curt said to her, “Put me to work! I want to get involved.”

Even before the meeting, Curt and Shonda had decided they wanted to give something back to the community, realizing there was much more to a complete life than a successful career and material wealth.

“We were at the point in our lives that we felt like we wanted to commit ourselves to something away from baseball and off the field. And ALS just seemed like the right thing to do,” said Curt.

Their commitment to ALSA has never wavered since their encounter with Bergeron, who passed away last year. They even named their first son after the person commonly associated with ALS, New York Yankees slugger Lou Gehrig.



Official World Series baseball signed by Curt Schilling

“We wanted his name, Gehrig, to symbolize life and happiness,” said Curt. “ALS and Lou Gehrig have stood for nothing but terminal illness for so long. When our son Gehrig walks into a room, the patients see a child full of life.”

The Schillings wanted all of their children to be involved in this cause – a cause they both believe has strengthened their marriage – so they bring the children to ALSA events. “Having the children at the Walk to D’Feet ALS® teaches them that we are put on Earth to take care of each other and how to get involved,” said Shonda.

The Schillings downplay the amount of funds they have raised. “It’s not enough,” insisted Curt, with Shonda nodding in agreement. “The number is absolutely, totally 100 percent irrelevant. It is not enough.”

Phillips, who has become a close friend of the Schillings, counts her blessings every day knowing they are on board for the long haul. “ALSA would not be where it is today as an organization if not for the Schillings,” said Phillips. “They are extremely devoted to the cause. They have a beautiful, strong connection to the cause. They’re out there walking the walk and talking the talk.”

A Giant Step to D'Feet ALS

It began as an idea suggested by ALSA's Western Pennsylvania Chapter, became a pilot project, and now, five years later, The Walk to D'Feet ALS® has become a fundraising juggernaut for The ALS Association and a great way to lift the spirits of people who have the disease.

The director of ALSA's signature national event, Pat Freiberg, is pleased with the progress of the Walk and is optimistic about the prospects for its growth as the event continues to financially pave the way for expanded services and programs for patients and their families.

Freiberg points toward such leading indicators as the increasing number of individuals participating – including more volunteers and donors – and dollars raised as proof that the event is well on its way toward achieving national stature in the eyes of the ALS community and the public at large.

> **"Participants find it energizing because when you come together as a community; there is so much strength and support, caring and compassion."**

Nearly 80,000 walkers last year participated in 135 Walks held across America in 133 cities. By forming teams in honor of a loved one, walkers raised nearly $8.7 million, six times more than when the event was launched in 2000.

Additional analysis reveals that this year there will be 145 Walks compared to 84 in 2002, close to a 73% increase in only three years. In total, the Walk has raised close to $30 million in the last five years.

"The Walk has turned out better than our wildest dreams," said Freiberg, ALSA's former DC/MD/VA Chapter executive director, a former psychologist who provides counseling to all ALSA chapters on how to plan fresh, fun and positive Walks.

Pat Freiberg, director of ALSA's signature national event

Equally impressed is Pam Rockcastle, family chair of the ALSA Evergreen Chapter's first Walk. Since 2000, she has participated in every Walk held in Seattle, Washington, first in honor of and then in memory of her late brother, Lorne Rockcastle, who lost his battle with ALS in 2003. She was skeptical in the beginning because of the low turnout; however, the Seattle Walk now attracts several thousand people. In all, Evergreen sponsors Walks in five Washington cities.

"It really turned out to be better than I expected," said Rockcastle, organizer of the family's Walk team named Lorne's Beepers. "The Walk has become so big that I do not even know some of the people there, which is a great thing."

To spark continued growth, a three-day training course was offered earlier this year in Austin, Texas, by national Walk sponsor Booze Allen Hamilton, a global strategy and technology consulting firm. Walk coordinators from most of ALSA's chapters attended and learned about best practices that can grow the Walk.

"During the training, each chapter shared its model for success, tried to help each other grow and collectively came up with new ideas," said Marilyn Simon-Gersuk, vice president of ALSA's Community Services Department.

"We want as many people as possible to know what we're trying to do to help people with ALS," said Simon-Gersuk. "We want people to know about the struggles people are facing because the more knowledge people have, the more they can be a resource and help, whether it is through donations or through community, state or national advocacy."

Freiberg believes the Walk has a therapeutic effect. "Many ALS patients and their families really look forward to the Walk. The Walk brings the ALSA community together in an upbeat way. It allows for hope. People want an opportunity to do something for someone with ALS, and sometimes they just do not know what to do. This gives them that opportunity."

"Participants find it energizing because when you come together as a community; there is so much strength and support, caring and compassion," added Simon-Gersuk.

The sphere of influence of the Walk also grew last year, with walkers wielding legislative clout far beyond the boundaries of their local community. As part of ALSA's new "I Took the Extra Step℠" program, walkers and volunteers were encouraged to sign a letter to a member of Congress highlighting one of ALSA's legislative priorities.

"The campaign has been tremendously successful at generating grassroots awareness and advocacy," said Steve Gibson, ALSA vice president, Government Relations and Public Affairs. "The 17,000 letters generated by the campaign demonstrate ALSA's ability to mobilize grassroots activists. Put in perspective, that is more than three letters to Congress for each of the estimated 5,000 people who were diagnosed with ALS in 2004. That is a powerful example of advocacy in action."

> **"The 17,000 letters generated by the campaign (I Took the Extra Step) demonstrate ALSA's ability to mobilize grassroots activists."**

Freiberg listens very closely to chapter representatives before offering advice. Like a sponge, she soaks up as much information as possible during in-person visits, over the phone or from the many e-mails she receives from chapter executive directors who want their Walks to be as successful as possible.

"I assume that when I'm out in the field, there are going to be dozens and dozens of great ideas," she said. "We have some really smart people across the country, and I've become a conduit for these great ideas on how to grow the Walks. Chapters want the opportunity for someone to come in from the outside and do 'Monday morning quarterbacking' about the last Walk and help them plan one for the next year."

"If any chapter asks her for help, Pat is there," said Simon-Gersuk. "She'll spend a couple of days with the Walk staff, really helping them to look at what they have done and how to move it ahead. She is very focused, hands on."

The Walk has come a long way since 2000 when 14 ALSA chapters sponsored 14 Walks.

"In 2000, I know we wanted all the chapters on board," Freiberg recalled. "After that first pilot year when it was clear the Walk would be successful, I'm not even sure if we ever thought that one day we would be able to raise more than $8 million."

When she was still a chapter executive director and there was only one other person to help her with the Walk during its inception, Freiberg hoped 500 people would participate in the chapter's Walk and raise between $50,000 and $100,000. Instead, 2,000 people showed up and raised a whopping $325,000.

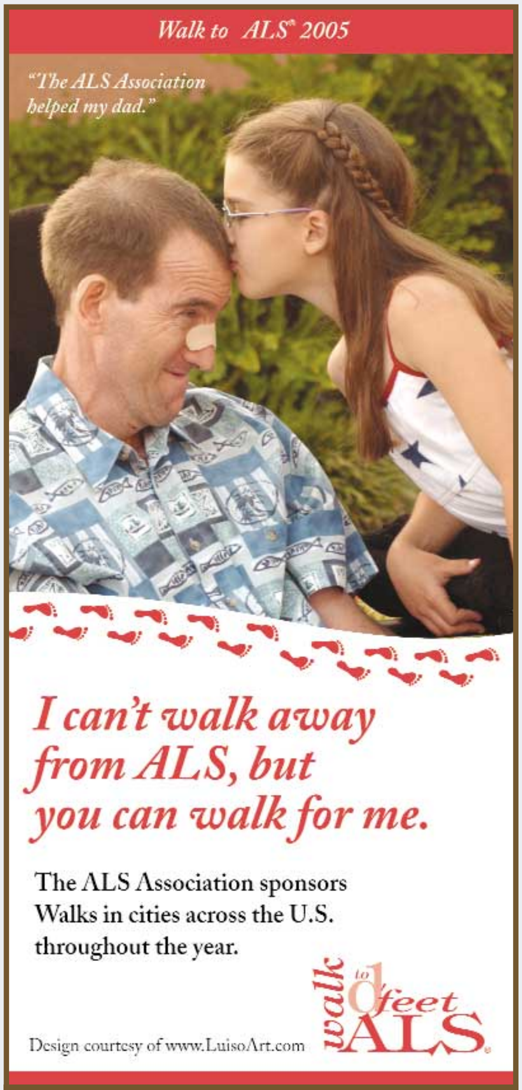
New chapters holding their first Walk are pleasantly surprised by the instant infusion of revenue that jump starts the programs they want to offer patients. "They actually don't know what is going to happen when they start an event, but afterward they call and thank me," said Freiberg.

One Walk sponsor related to Freiberg an aspect of the Walk to D'Feet ALS® that sets it apart from other fundraising events. "He told me that when you go to other events, they start off as teams, but some people decide to run and some walk. They do not seem to stay together. At ALSA, the participants are very much centered on patients and sometimes patients who are no longer living. You really get the feeling that these are family teams, and family and friends stay together."

The key to an increasingly successful Walk is rooted in how much more convenient it has become for participants to register and form teams. They can sign up online by visiting any one of the ALSA chapters' websites. Everyone who joins the Walk can, at their own option, have their own web page and send out letters and e-mails to their friends and family.

Even the children of patients cannot resist the appeal of the Walk. In Cincinnati, Ohio, 12-year-old Christian and 13-year-old Paul Carey, a real "Dream Team" if ever there was one, raised more than $75,000 for ALSA's Western Ohio Chapter Walk. Approximately 550 walkers joined their "Kids 4 Cure" team; many recruited through the chapter's web site, to help out their mom, Lori Carey.

With supporters like these, "The sky is the limit," said a beaming Freiberg. GW



The ALS Association sponsors Walks in cities across the U.S. throughout the year.

Design courtesy of www.LuisoArt.com

Brochure cover for 2005 campaign

ALS Advocacy

A conversation with ALSA's Vice President of Government Relations and Public Affairs

Holding a degree in history from the University of California Los Angeles, Steve Gibson has worked in many different government agencies. In 1997, Gibson opened ALSA's Advocacy office in Washington, D.C. The following year in May, the first National ALS Advocacy Day was held. Since then, the event has grown to a 3-day conference that will be held May 9–11 this year. Gibson led ALSA's effort to encourage Congress to waive the Medicare 24-month waiting period for people with ALS.

HOPE: What's the purpose or the charter of ALSA's advocacy function?

GIBSON: Seven years ago, the leadership of The ALS Association decided to establish an advocacy department to help with ALSA's mission of finding treatments and a cure for ALS, primarily by raising more federal funds for ALS research and finding additional resources to better care for people with ALS and their caregivers.

Lori Reed, Board Member of the Greater Sacramento Chapter with Steve Gibson in Washington D.C.

HOPE: Would you describe how you interact with members of Congress?

GIBSON: The key to working with members and their staff can be summed up in one word, relationships. Having been in Washington, working in the White House and working for a U.S. Senator, I've been able to establish a number of important relationships that clearly helped to further our mission. Many grassroots advocates who come to Washington, D.C., have helped us develop relationships on the Hill. Regardless of their background, people who have had to deal with this devastating disease develop a common bond. Seeing the horrors of ALS, they really want to do whatever they can to eradicate this disease—and time is of the essence because most people with ALS have so little of it. Congress is a slow-moving, bureaucratic system, and relationships play a role in developing priorities. A member's role of leadership in terms of committee assignments is a major component. However, the staff is the focal point of the relationship because they usually focus on a few issues at a time, while the member has hundreds of issues and not all pertain to health care. The staff can help get a member to co-sponsor a piece of legislation, focus on an issue before a hearing or influence language in an appropriations bill involving ALS.

HOPE: How do you go about setting the annual public policy agenda?

GIBSON: Several years ago, we initiated a practice we call a "listening tour," where we collect the important issues from the ALSA family. Beginning in November, when Congress adjourns, we visit with ALSA trustees, public policy chairs, patient service coordinators and executive directors. We evaluate the issues to see how many people with ALS or caregivers the issue impacts. We look for coalitions that may be able to help us; we try to leverage our effort. We consider the potential of the issue being acted upon in the coming year, then, we rank the issues in order of importance to our constituents and select one to three issues, which are presented in February. However, we can make adjustments throughout the year in case a larger bill may be introduced that we can attach our issue to. The reality is that if we have more than three issues in one year, it's hard for members of Congress to do much with our agenda.

HOPE: What are some of the major accomplishments of ALSA's advocacy program?

GIBSON: Since 1997, when the Washington, D.C., office was established, we've helped increased federal funding for ALS research by almost 300 percent, from about $15.1 million to about $44 million, which is remarkable for an orphan disease like ALS. We helped to establish a special funding mechanism in the Department of Defense that will shed more light on the environmental factors of this disease. Because of our efforts, ALS is one of two diseases for which the Medicare 24-month waiting period has been eliminated. In 2006, when the Medicare benefit goes into effect, people with ALS will be able to have drugs two years sooner to treat symptoms of this disease.


Steve Gibson consults with actor and ALS advocate Blair Underwood.

HOPE: What are the major challenges to having a successful advocacy effort?

GIBSON: Unfortunately, the legislative process does not lend itself to quick and easy victories. It takes several years to move a bill through Congress. While the process is very slow, the disease is very fast. Consequently, 50 percent of the advocates that come to Washington are brand-new. It takes time to train them to be effective on Capitol Hill. However, these advocates demonstrate a sense of urgency that makes an impression, so the members of Congress make the extra effort to get things accomplished. For example, in the Medicare waiver bill that passed, we were very fortunate to have a leader like California Congresswoman Lois Capps. On the day she was sworn in, she introduced herself and said: "I want to help you and pass this bill," a bill her late husband had introduced. She tried to attach that legislation to any bill that moved in the House. As we started to focus on the bill and its passage, there were many seasoned healthcare lobbyists that said "don't waste your time" because they believed a bill that would give an exemption to just one disease didn't have a chance. Fortunately, there was a large bill that we could attach it to at the end of 2000. With the support of President Clinton, it passed.

HOPE: The National ALS Advocacy Day and Public Policy Conference is held each year in May, which is also ALS Awareness Month. What are some of the major activities, and what do you hope to accomplish?

GIBSON: We have a very strategic effort on Capitol Hill. We recruit advocates from key jurisdictions throughout the country whose members sit on key committees. Last year, 600 people from 43 states met with 389 members of Congress. We have expanded our efforts to include an educational effort where we invite scientists from the NIH (National Institutes of Health) to share what's happening with the funds we've helped Congress appropriate for ALS research. We also focus on future issues that need to be more refined before introducing to members, such as working with the pharmaceutical industry to encourage more involvement with an orphan disease like ALS. Last year, we initiated an annual candlelight vigil on the steps of the majestic Jefferson Memorial, where we took a moment out of our three days in Washington to share experiences to help remind us why we were in Washington and to reflect on how much more work we have to do.

HOPE: How has the Congressional environment changed in recent years regarding ALS?

GIBSON: The Congressional environment is very partisan, and each party is promoting their agenda. There is a huge deficit, and this administration wants to keep the budget numbers down. Many advocates from a great number of voluntary health groups are pushing their agendas, in addition to the vast number of advocates of non-healthcare related issues. Even though ALS is a rare disease, we're still at the table with the more prevalent diseases, such as Alzheimer's, which affects 4.5 million people. In 2000, a hearing specifically on ALS was held, a first for any rare disease. We sponsored awareness activities on Lou Gehrig's hundredth birthday. We had successes, but we need people to come to Washington to keep the momentum going to share the sense of urgency, which can influence members of Congress to act on our behalf.

HOPE: Would you like to make any final comments?

GIBSON: Often, people weigh our accomplishments in terms of whether or not we have found a treatment and a cure for the disease, and we won't be satisfied until that day comes. But, it's important to look at what we've accomplished as an organization with such a small budget and staff. Everyone in this organization understands the urgency. Also, many people think of ALS as an older person's disease; however, many advocates are young people with families. That sends a different message. People on Capitol Hill pay attention to young people, especially children. This year, our youngest advocate was 11-year-old Jason Metcalf from Florida. He became involved with ALSA because his best friend, George Chapman, died of ALS. He is continuing his advocacy and awareness effort and plans to return to Washington next year to tell his story.


Jason Metcalf receives Packman Award (for expanding awareness of ALS) from Gary Leo, ALSA's president and CEO

Physician, Patient, Disease
Triangle of Irony

He hoped the stiffness and incoordination that he first began experiencing in his right leg in August of 2003, eventually followed by progressive weakening in both legs, was caused by the compression of a disk in his spinal column. A bad back, after all, could be overcome. When the condition spread to his arm in May of 2004, he knew that his back was not his most serious problem.

> **“Dr. Olney is internationally known for his clinical innovations, compassionate care, dedicated teaching and groundbreaking research.”**

Nearly one year after his symptoms began, and after three back surgeries, the internationally renowned Dr. Richard Olney, a man who devoted his medical life to treating and comforting ALS patients, as well as conducting important ALS research, would be told by doctors treating him that his suspicions were true. He had ALS.

Most people, upon hearing such news, would likely have sat in stunned silence, not the 57-year-old Olney, who helped found the ALS Treatment and Research Center at the University of California, San Francisco (UCSF), an ALSA certified Center of Excellence. For months he had realized his symptoms matched those of the ALS patients he had treated for three decades, and that statistically the chances of an ALS doctor one day developing the disease was well within the realm of possibility.

During that June 2004 office visit – in this hour of introspection – Olney’s thoughts turned to his Hippocratic Oath. His patients would need to be told as soon as possible about his condition and that, regrettably, he no longer could care for them. And then there were his friends and family members, who loved him dearly. They would need his help, too, in learning how to lend support to a person who had been a pillar of strength to them and within the ALS community.

“One week after I received the diagnosis, I wrote a letter to all of my patients so everyone would know the truth quickly without hearing it through the rumor mill,” recounted Olney, now relegated to an electric wheelchair. “I told them I would be closing my practice and would not be able to see them myself.”


Richard Olney on the set of ALSA public service announcement

During a reception last August at the Millberry Union Building, Olney found that the patients returned the warmth and affection he had shown them. Patient after patient, verbally and on the back of RSVP cards, thanked him for his many years of dedication and wished him well.

Typical remarks were: “We hope your doctor was as gentle and caring when telling you that you have ALS as you were when you told us,” and “Your kindness and encouragement have helped me accept and deal with my diagnosis and are a fundamental reason I’ve maintained my normal optimistic frame of mind.”

One of the limitations Olney has had a difficult time coming to grips with is not being able to treat ALS patients. Nowadays, it is their memories that motivate him to fight on.

Olney recalls one patient, a woman who had familial ALS. “She had seen a number of her family members go through the illness and knew what she was facing, much as I do. She was one of the happiest and most outgoing people I’ve ever known. One way she coped with the disease was to allow herself to be sad and cry for 30 minutes each morning and then be happy and enjoy the rest of the day.”

Just as he told his patients, there is a lot of living left, and he was going to make the best use of his time. Olney vowed to be an ALS patient role model. He did not want to be a hypocrite in the eyes of those he had treated and looked to him for hope. The first dose of his own medicine was to maintain as active of a lifestyle as possible.

“I’m trying to set a legacy of being a very cooperative patient, one who is actively engaged not only in performing ALS research, but being a subject.” He is participating in a placebo-controlled trial he helped design.

Olney admits that being an ALS physician and researcher has given him an

Paula and Rick Olney during Alaskan cruise

advantage in adjusting to the disease. "I've learned to focus on the things that I can influence – and just accept those that I cannot influence," ruminated the esteemed lecturer and extensively published author of scientific articles.

His advice to patients carries more weight today than ever. "Personally, and for all ALS patients, it is important to position yourself in the most supportive environment for yourself, as well as your family, in the pursuit of treatments that are the most scientifically credible, such as the drug treatments offered by ALSA Centers," he emphasized.

"I'm trying to set a legacy of being a very cooperative patient, one who is actively engaged not only in performing ALS research, but being a subject."

An avid outdoorsman, world traveler and movie buff, his stay active philosophy includes visits to UCSF three times a week for exercise sessions. In addition, he has participated in media interviews and filming a public service announcement for ALSA, which also featured actor Alan Rosenberg, who portrayed an ALS patient on the CBS series "The Guardian." He even took a cruise to Alaska with his wife Paula. The two had planned the trip long ago for their retirement years.

Even after his diagnosis, Olney spent a good portion of his day conducting research on a project funded by ALSA titled "Multicenter study of environmental and genetic factors that influence the initiation or rate of progression of ALS and its phenotypes."

"The ALS Association makes a very important contribution to ALS research," said Olney. "In particular, they fund very novel ideas and let people develop the preliminary data that they would need to go to the National Institutes of Health to apply for larger grants. ALSA serves a major role in helping people get started in their ALS research."

Stephen Hauser, M.D., chair, UCSF Department of Neurology, acknowledged Olney's contribution to patient care and research by saying, "Dr. Olney is internationally known for his clinical innovations, compassionate care, dedicated teaching and ground-breaking research. He is a strong believer in the team approach to the complex care of patients with ALS."

"ALSA serves a major role in helping people get started in their ALS research."

Despite the major improvements he has witnessed and helped bring about, Olney would like to see more of an outreach effort made to remote regions without ALSA Centers as well as the acceleration and number of drug trails.

"Dr. Olney's contributions to ALS research and his involvement in pilot clinical trials are invaluable to the field," said ALSA's Science Director and Vice President Lucie Bruijn, Ph.D.

He was the first and only chair of ALSA's Bay Area Chapter Patient and Family Services Committee, helping the chapter expand from a small information and referral-based operation to offering comprehensive regionalized service.

"Under his leadership, the chapter's responsiveness to patients and their families grew tremendously," said Linda M. de Mello, ALSA's Bay Area Chapter executive president. "Dr. Olney's vision and ability to build consensus among disparate groups allowed the chapter to thrive. The contributions of Dr. Olney will be felt by patients and families for many years to come."

Two accomplishments immediately come to mind when Olney is asked to list some of the many milestones in his life: the founding of the ALSA Center and his family.

"Having developed a loving family and two children, who have grown up to be loving, compassionate people – who I think are going to be very productive members of society. Certainly raising two great children are two of my proudest accomplishments in life."

Both children, Amy, 24, and Nick, 27, have moved back home to help Paula take care of their father.

Because of the hard work and devotion of physicians and researchers like Dr. Richard Olney, there is a much better chance that ALS one day will be relegated to medical books that describe diseases that no longer plague the world.

"There is so much knowledge that is being developed at an accelerated rate," Olney points out. "There are more researchers becoming involved with ALS. Ultimately, a cure will be found in some reasonable period of time, at least from an academic point of view. In the foreseeable future, there is every reason to believe there will be marked advances in treatment." GW

The Olney family: Nick, Paula, Rick and Amy

MARY ANN WILDE

Beyond the Loss – Love and Commitment Thrive

By Janet Young

"When my husband lost his life to ALS, I knew I had to continue to stay involved with the ALS community," shared Mary Ann Wilde, a long-time supporter of The ALS Association. "I had to do something to help patients in my own community and across the country who are battling this disease."

"ALS can progress so quickly that you may think you don't immediately need a wheelchair or other adaptive equipment."

Harold Wilde, Mary Ann's husband, passed away in 1998 at the age of 76, two years after receiving the diagnosis. He first noticed symptoms in 1993. It took specialists three years to confirm that the muscle weakness he was experiencing could be attributed to ALS.

"After his diagnosis, Harold was absolutely amazing," Mary Ann said. "He had been a driven man all his life, and now he allowed himself to stop pushing, to relax, and to enjoy what he had. For someone who was used to being in charge, it was inspiring to see him adapt the way he did to the illness. Throughout it all, he never lost his temper, and he always maintained his sense of humor."


Harold Wilde

Born in 1922 in Muskegon, Michigan, Wilde worked his entire career in the automotive business. Returning from service with the Army Air Corps during World War II, he opened a used car lot in 1945, fulfilling a lifelong dream to work in the automotive business.

In 1961, he met Mary Ann when he purchased his first Lincoln Mercury dealership. Wilde had one daughter, Susan, from a previous marriage. Together, Mary Ann and Harold had three other children, Kathleen, Tracie and Mark.
At the time of his death, Wilde owned 15 automobile franchises. He was also President of Wilde Productions, Inc., the advertising and marketing agency for his automobile businesses.

Today, Mary Ann, along with son, Mark, and daughter, Tracie, have assumed the reigns of the Wilde Auto-motive Group. As President of Wilde Automotive, Mary Ann oversees thriving dealerships in Florida and Wisconsin. She also remains steadfastly focused on helping those living with ALS.

"We have to find the answers…it is through research that we can unlock the secrets to ALS."

For the last five years, she has hosted the Harold L. Wilde ALS Golf Invitational. Proceeds from this highly anticipated and very successful event help support the Harold L. Wilde Loan Closet in Sarasota, Florida, as well as The ALS Association's premier ALS research program.

"When you are caring for an ALS patient, there is just so much you need," Mary Ann said. "Our family was very fortunate that we were able to obtain the equipment necessary to help keep Harold comfortable. Many families cannot. Our support of an equipment loan program helps to ensure that patients in our community can have access to those things they so desperately need.

Through the Harold L. Wilde Loan Closet, patients in the Sarasota area can obtain canes, walkers, wheelchairs, shower chairs, recliners, braces and transfer boards, as well as sophisticated communication devices and state-of-the-art BiPap machines. These items are loaned out to those who have no insurance coverage or funds to buy them. In existence for four years, the Harold L. Wilde Loan Closet has provided equipment free-of-charge to approximately 75 ALS patients in the Sarasota area.


Celebrating the life of Harold Wilde at last year's golf tournament are Mary Ann Wilde (center) with Tom and Mary Makarewicz

"One of the challenges I faced as the primary caregiver was having the necessary items in place before they were needed," Mary Ann explained. "ALS can progress so quickly that you may think you don't immediately need a wheelchair or other adaptive equipment. Having the equipment in place in advance, however, made Harold's life so much easier. I want to ensure that others battling ALS have the access to this equipment and that it is in place when they need it."

"It is so very important to find the genes related to ALS."

"Mary Ann has done so much for ALS patients in Florida. She is a very compassionate and caring person, and the ALS community is lucky to have her on their side, fighting against this disease," shared Dara Alexander, executive director of ALSA's Florida Chapter. "Mary Ann's magnanimous support demonstrates that she understands the need and importance of funding ALS research."

"We have to find the answers," said Mary Ann. "We have to understand what causes this disease so we can take steps to slow and stop its progression, and ultimately, eradicate it. It is through research that we can unlock the secrets to ALS."

"To date, the Harold L. Wilde ALS Research Fund has given more than $350,000 in support of ALS research through The ALS Association. Mary Ann's steadfast support ensures that we can fund the leading edge research that is so vitally important," said Lucie Bruijn, Ph.D., ALSA Vice President and Science Director.

The Harold L. Wilde ALS Research Fund is currently supporting several groundbreaking research projects, including the Gene Identification Project, the most promising familial ALS research project since the discovery, in 1993, of SOD1, the gene linked to 20% of familial ALS cases. Using technology derived from the Human Genome Project, scientists hope to identify the mutations and genes linked to familial ALS by employing large-scale DNA sequencing. Because scientists can now sequence large regions of chromosomes in a shorter period of time, there is strong hope for identifying genetic mutations that may be linked to ALS more rapidly. The discovery of disease-linked genes will provide valuable information in understanding the mechanisms of cell death not only in familial ALS, but also in sporadic ALS, which represents the majority of ALS cases.

"For my children, and for the children of ALS patients around the world, it is so very important to find the genes related to ALS. We need to know if families with a connection to ALS are more at risk," Mary Ann said.

Another project she is particularly interested in is the clinical trial of Myotrophin (Insulin-Like Growth Factor or IGF-1). The objective of this trial is to determine whether Myotrophin can slow the progression of weakness in patients with ALS.

"From day to day, you never know what to expect with ALS. Every week we could see the changes in Harold as the disease progressed," Mary Ann explained. "There was nothing we could do. Research such as this can provide hope to patients that the disease progression can be slowed."

"Mary Ann is a truly amazing person," added Gary Leo, ALSA President. "She has not let the loss of her husband stop her. Rather, she has turned that loss into something beneficial - providing hope to ALS patients everywhere. All of us at The ALS Association are truly grateful for everything she has done and continues to do on behalf of ALS patients and families."

"She has not let the loss of her husband stop her. Rather, she has turned that loss into something beneficial - providing hope to ALS patients everywhere."

"What we have done is almost immortalized Harold by our support," Mary Ann said. "And I am so glad that we are able to do that. This way, people who never knew him can still gain a sense of who he was and the important role he played in our lives. His legacy will forever be one of helping others, and I know he would be very pleased with that."

For more information about ALSA's research program visit http://www.alsa.org/research

LIVING WITH ALS
MEET THE OVER FIVE CLUB

By Katie Sweeney

Lee Kramer has a message for ALS patients: There is hope – and he's living proof of it.

Kramer, 57, has been living with ALS for more than 13 years, far beyond the two-to-five-year timeline doctors gave him when he was diagnosed. And he's not alone. Over the past eight years, he's corresponded with more than 150 long-term survivors of ALS.

Those survivors make up The Over Five Club, a special group Kramer started for people who live more than five years with the disease. The club, founded in 1997, is mostly informal. Kramer tracks members' disease progression and what they do to cope, and sends the data to ALS researchers. He also sends official certificates to members as they reach ALS anniversaries of five, 10, 15, 20 and even 25 years.

The club serves a larger purpose, too. "We need to let the newly diagnosed know there is hope," says Kramer, who lives in Napa Valley, Calif., with his wife, Anne, and their youngest daughter, Andreana. "That's our mission."


Clockwise from left, Lee's sister, Debbie Mack; Debbie's husband, Jim; Anne Kramer and Lee.

He got the idea for the club after chatting with other long-term survivors through an e-mail group he helped start, "Living with ALS," which he co-founded with David Jayne and Julie Scurich. Most club members are people he's met through that group, and they come from all over the world, including Australia, Canada, Guatemala, India, Belgium and Japan. One of the club's most famous members is physicist Stephen Hawking, who has had ALS for more than 40 years.

The club's existence doesn't surprise Rup Tandan, M.D., M.R.C.P., medical director of the ALSA Certified Center$^{\text{SM}}$ at the University of Vermont College of Medicine in Burlington, Vt. "We are seeing an increasing number of people surviving over five years with ALS," Dr. Tandan notes.

> "We are seeing an increasing number of people surviving over five years with ALS."

Although the median survival rate for ALS is three to four years, some patients live much longer. "It's generally believed that 10 percent of patients live 10 years, and five percent live 20 years," he says.

The reason why is unknown. Some patients' disease progresses very slowly, or even stabilizes, he explains. Ventilators and BiPAP machines also may prolong survival substantially.

So what's life like for The Over 5 Club? Cindy Blacker of West Palm Beach, Fla., was diagnosed with ALS in 1996. Today, she is mostly, but not completely, paralyzed and can speak and eat some food on her own.


Daughter, Victoria, arranged for Lee to attend the San Francisco 49ers football training camp. Shown from left are Victoria, Lee and Guy McIntyre, 49ers' player development director.

Her biggest challenge came in 2001, when she lost her husband to colon cancer. "When that happened," she says, "I thought I wasn't going to make it."

But she did. Her son, Michael, came home to live with her, and she found a new hobby in buying and selling collectible items online.

"I'm a stubborn, determined person," says Blacker, 55. "I refuse to think about the bad. That's not to say I don't get upset. But I get over it and keep going on."

> "We need to let the newly diagnosed know there is hope."

Another club member, Charlie Wedermeyer, has had ALS since 1976. The former college football player is on a ventilator and can only move his facial muscles. But with the assistance of his wife, Lucy, and dedicated friends, he helps coach the junior varsity foot-ball team at Los Gatos High School in Los Gatos, Calif.


Lee and Anne Kramer enjoy a moment with "Lou Seal" (team mascot) at a San Francisco Giants baseball game in 2003.

"No one is promised tomorrow," Wedermeyer says. "We don't put things off anymore."

Kramer went on a ventilator last year and has adjusted well. He's in a wheelchair with only partial use of his left hand, but he stays active, leading the club and a Napa support group, and serving on the board of directors for the Greater Bay Area Chapter of The ALS Association.

A Vietnam veteran, Kramer spent 22 years as a U.S. Army paratrooper, earning a medal collection that includes four Purple Hearts and a Bronze Star.

His advice to fellow ALS patients? "Go live life!" he says. "Do as much as you can for as long as you can. This is just another life challenge."

For more information on The Over 5 Club, contact Lee Kramer at ranger-1@pacbell.net or (707) 255-7327.

LEGACY OF

HOPE

Laura's Story:

A Family Affair *By Juan Ros*

Laura Stanley knows the toll that ALS can take on a family. In her case, that toll has been devastating: since the early 1900s, 27 members of Laura's family – including her mother, grandfather, and most recently, her brother David – are known to have died from ALS. Her cousin, Pavia Wald, is fighting the disease today.

Laura doesn't know if she is carrying the familial ALS gene that gives her a 50% chance of being diagnosed with ALS in the future, but that hasn't stopped her from becoming a determined, tireless advocate on behalf of The ALS Association. "I'll do whatever it takes to help find a cure," she says. "There is hope if people become involved."

Laura speaks to student and civic groups, traveled to Washington, D.C., for ALSA's National ALS Advocacy Day Conference, and helped raise more than $200,000 for the Orange County, California, Chapter's Walk to D'Feet ALS®. Laura's daughter, Sarah, is following her mother's lead. For her eighth birthday, Sarah asked that money be donated to ALSA in lieu of gifts. Between those gifts and a car wash organized by her friends at Tutor Time, a child care and learning center, Sarah raised more than $2,600.

Laura's commitment to fighting ALS also led her to take an important step: remembering The ALS Association through a bequest in her will. "The ALS Association definitely needs money for research," Laura points out, "and I want to help other families facing ALS."

Although in her early forties, Laura did not want to wait before making her bequest. "It's never too soon to make a bequest," she explains. "You need to be prepared, to make sure your affairs are in order, and your intentions are clear for those who are left behind. I've learned this the hard way. You never know what God has in store for you."

Pictured are Laura's brother David (center) with family members. Clockwise from lower left are Laura's daughter Sarah, cousin Helen Harper Ammer, sister Carol Stanley Ritt, David's daughter Cherly Stanley, Laura and cousin Pavia Wald, who also has ALS.

With her legacy secured, Laura will continue fighting for her family for as long as it takes. She knows that ALSA will be there for her and others, funding research and serving ALS patients like her brother. "The ALS Association provides great support. The love there is amazing."

DESIGNS FOR GIVING

You can make a difference by leaving a legacy of hope through a gift in your will or trust to The ALS Association. Your gift can benefit the National Office, your local ALSA Chapter, or both. For more information, please call Juan Ros, Director, Gift Planning, toll-free at 888-949-2577, extension 212. Or visit the Gift Planning section of our web site at www.alsgift.org. Your inquiry will be strictly confidential.

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We would be happy to provide more information on how you can include The ALS Association in your estate plan. Check out our web site at www.alsgift.org or contact us at:

Juan Ros, Director, Gift Planning
27001 Agoura Rd., Suite 150
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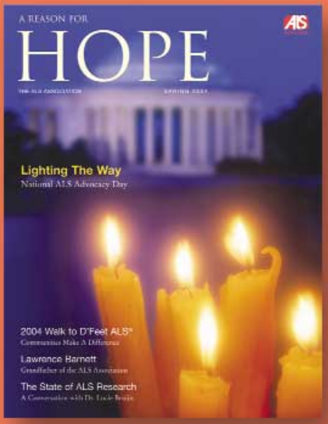

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