HOPE

A REASON FOR

THE ALS ASSOCIATION

SPRING 2007

ADVOCATES GO TO CAPITOL HILL

BRAIN-COMPUTER INTERFACE OFFERS HOPE

ON THE ROAD WITH ALS

WINNING TEAM: Walk to D'Feet ALS and Baseball

ALS Association
Fighting Lou Gehrig's Disease

SPRING 07

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THE ALS ASSOCIATION
SPRING 2007

By Roberta Friedman Ph.D.
Staff Writer

A newly-discovered link between ALS and a type of cognitive change called frontotemporal dementia (FTD) may provide new access to common biology underlying the two conditions.

A Common Link Gives New Clues for ALS

The spotlight now shines on a mysterious protein called TDP-43, found in affected tissue in both diseases. If confirmed in a wider set of ALS patients, the protein could prove to be a missing link to a shared disease process.

For the past five years, investigators have attempted to solve what links ALS to FTD. Some people with FTD, a dementia different from Alzheimer's, also have movement problems, and some people with ALS will show slight cognitive changes resembling FTD. Estimates are consistent that about a third of ALS patients have some mild cognitive loss, while only a small percentage of ALS patients will have definitive FTD.

Researchers Lee, Neumann and Trojanowski

The ALS Association helped to sponsor the first international conference last year on FTD and ALS and is working toward effective therapies as well as ways to improve quality of life for affected families. Several research efforts funded by The Association are underway. For instance, University of California, San Francisco investigator Catherine Lomen-Hoerth, M.D., Ph.D., is finding a simple way to predict which ALS patients risk cognitive change. Undoubtedly, collaborations facilitated at the conference and through continued funding helped steer attention to the relationship between FTD and ALS.

Cognitive Change

For people with FTD, their memory remains intact, for the most part, but their speech can be affected in that words may not come easily. The hallmark symptom is inability to make appropriate social decisions.

While more than half of FTD is inherited, only about 10 percent of ALS runs in families. Nevertheless, some common process is likely. Both may represent points on a continuum of nervous system damage stemming from a common defect. Now that defect can be investigated using the TDP-43 protein as the starting point.

Key to the protein discovery was a special contribution by ALS patients in the area served by The Association's Greater Philadelphia Chapter. After patients passed away, families donated tissue, and when University of Pennsylvania investigators identified the protein in FTD cases, they had ALS samples on hand.

University of Pennsylvania researchers Virginia Lee, Ph.D., and John Trojanowski, M.D., Ph.D., together with German researcher Manuela Neumann, found TDP-43 protein while making an antibody to study the abnormal deposits present in FTD. Making antibodies that stick to a protein of interest is a time-honored method in molecular biology, but it can be hit or miss. In this case, the researchers hit their target. The antibody served as a handle to pull out the protein from the tissue, allowing the scientists to identify it.

The investigators used a detector called a mass spectrograph to see the pattern of atoms in the protein, a pattern matched by TDP-43.

TDP-43 in ALS as Well

The scientists immediately showed their antibody also tagged the deposits in all the ALS cases they examined.

Scientists have not yet studied TDP-43 in great detail. That is likely to change as the spotlight shifts to TDP-43. Knowing the common protein in two diseases should stimulate the effort to find out what it does, and why it is deposited in the motor neurons in ALS and in the neurons of the frontal and temporal cortex in FTD. The new finding should accelerate progress toward effective therapies.

Misfolded disease proteins (deep red) in neurons of the hippocampus

Lift makes it easier for Stuart Obermann to get his son Eric into the van.

Andrew Fleeson

Using a rented scooter, Jane Drury plays croquet with son Bob during a trip to Vermont

The Road Less Traveled

→ Trave

According to one famous travel book, more than half of all people who go on a trip encounter problems.

This undoubtedly applies to people with ALS. Whether it's finding a wheelchair-accessible hotel or boarding an airplane, those living with ALS often meet such challenges but don't allow these occurrences to keep them at home. With a little incentive, lots of planning, and assistance from technology, patients can journey across the country or to faraway lands.

Welsh-born Andrew Fleeson maintains a busy travel schedule. Fleeson, who has had ALS since 1983 and uses a power wheelchair, is on the road on average every six weeks. During the past year, he has visited Chicago, Miami, Minneapolis, Washington, D.C., London, England, and Newport Beach, Calif. The 61-year-old Arizona resident plans for his trips using a laptop that employs speech recognition software and a program that lets him make phone calls. **"The device I use more than anything is my computer," Fleeson says. "It has become my lifeline to the world."**

This lifeline allows Fleeson to select airline flights or hotel rooms. He prefers to arrange his own travel as most travel agents don't understand the needs of those in a wheelchair. **"When I book a hotel, I need to know I will be getting a wheelchair accessible room, one with a roll-in shower," he says. "I research hotels on my computer, and then I phone the hotel to schedule my reservation."**

For the Obermann family of Huntsville, Ala., planning for a trip entails following lists and having necessary supplies available for their journey. Stuart Obermann and his wife, Marcia, have taken their son, Eric, 24, to Birmingham, Ala., St. Louis and Washington, D.C., for The Association's National ALS Advocacy Day and Public Policy Conference. Eric, who has lost complete use of his body and can only move his thumb, received his ALS diagnosis in 2000 when he was a student at Georgia Institute of Technology.

"What's made traveling easier for us is being organized and following the lists Marcia makes," notes Stuart. Marcia refers to a three to four page document enumerating the items required for Eric to travel. **"The list includes medical supplies ranging from pieces of a trachea tube to ventilator tubing to Eric's medications,"** Stuart says. A rolling "emergency suitcase" houses these items along with a binder holding the names of Eric's doctors, an emergency contact list, medical equipment user guides and a list of medications.

In addition, the Obermanns use small plastic cases to stock and transport needed materials. **"For example, we have a variety of bins for storing equipment, food and supplies,"** Eric says, via a speech synthesized computer. **"We also have a tall plastic eight-drawer rolling container that stores all of my medications. We use masking tape to hold the doors closed during travel. This portable equipment case makes it easier to move all of our gear in and out of hotel rooms."**

As Eric depends on myriad of devices for daily living, the Obermanns also take portable versions of equipment, including a suction machine, battery chargers, food pump, laptop ventilator that attaches to Eric's powered wheelchair, cough assist machine, folding ramp, powered chair lift, patient lift that transfers Eric to his wheelchair from a bed (and vice versa) and shower and commode chair. The family uses a wheelchair-accessible van to transport Eric in state or across the country.

Eric travels solely by van since being wheelchair bound. **"It's fairly comfortable for me,"** he says **"and we can fit in all of my medical equipment and my family's luggage."**

By Stephanie Dufner
Staff Writer

Storage for supplies and power chair with portable ventilator

Hotel roll-in shower

lingwithALS

While such a van is one mode of conveyance for patients, others opt to use the airlines to get from city to city. Chemist-turned-homemaker Jane Drury has lived with ALS for more than three years. During that time, she and her husband William have visited Kauai in Hawaii, Sarasota, Fla., and have sailed around the Canadian Maritimes on a cruise ship.

"We have flown to Florida and probably will again this year," admits Drury, 74, of Chelmsford, Mass., who gets around her home and public establishments with assistance from a folding transfer chair William pushes. The chair gets her to the airline gate, so she can board the plane.

"The transfer chair is light (17 lbs.), folds easily, and the airport people love it," Drury says. To navigate the airline's aisle on board, Drury holds on to the back of seats to get to the restroom and utilizes a cane to exit the plane down the jet way until she reaches her transfer chair. The airlines will either check the chair in cargo or stow it in a closet at the plane's passenger entrance door.

Fellow flyer Don Taylor, 56, thinks it's best to alert the airlines of any special accommodations patients may have.

"We have learned that when flying we need to request a seat with a 12-volt plug for my bi-pap machine," Taylor says, who lives in the town of Helotes, Texas, which is west of San Antonio. Taylor has bulbar ALS and has lived with the disease for the past three years, but he and his wife Patty travel two to three times a year. Taylor communicates with a laptop computer.

On one flight, Taylor needed to use his bi-pap machine which assists him with breathing. He was traveling with his son, Jeff, who read in an in-flight magazine that the airlines offer 12-volt adaptors on some of their seats.

"I was having a problem breathing and was using an ambu bag (a portable resuscitator that provides artificial ventilation) when my son found the article [about adaptors]," recalls Taylor.

"We asked the flight attendant if there was an adaptor in either of our two rows, and there was not." After Taylor's son firmly explained the importance of the situation, the attendant, with some reluctance, located a passenger sitting in a seat with an adaptor. **"She (the passenger) was very nice and moved over one seat, and I got my bi-pap plugged in,"** Taylor says. "It made the trip much nicer for me."

The Association's chapters can help patients have a more pleasant travel experience. Chapters in Missouri and Florida have assisted the Obermanns in finding local health care organizations when they stay away from their home for a night. Eric requires nightly assistance to turn in bed every two hours to prevent his body from getting bed sores.

"When we visit St. Louis, we work with the chapter there to find a nurse who is familiar with working with ALS patients," Stuart says.

"Local Chapters are a great source for finding agencies that give aid," states Fleeson, who needs help getting to and from his wheelchair in the morning and at night. He credits among others the Minnesota Chapter with giving him direction in locating home health care workers for these needs.

Taylor offers advice to other patients on travel. **"If you like to travel, DO NOT allow this disease to stop you. Make sure to pack everything you need and take backups if you have them,"** advises Taylor. **"Do not be afraid to contact the local ALS Association for help."**

"Plan ahead—call hotels to ensure they have adequate accessibility," recommends Eric.

Gate to Independence

Brain-Computer Interfacing Promises Aid in ALS

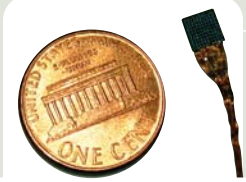
A five-year-old bounded into the room, wondering what his dad was up to. It looked like one of those old time computer games, where the players go for the bouncing dot.

He wanted to play, too. The guy helping his father told him to say where his dad should send the dot on the screen. And though the boy hadn't yet learned the way to tell left from right, he eagerly joined in.

This child is also too young to remember the last time he heard his father's voice. That is because his dad is in the advanced stages of ALS, Lou Gehrig's Disease, and cannot walk or talk any more. But, thanks to a tiny electrode recently placed on the surface of his brain, this father can hope to play with his son. He may perhaps, also gain a measure of control and independence through the messages still generated by his motor cortex, the part of the brain that usually commands the voluntary muscles to contract.

The BrainGate Neural Interface System is now in ALS patient trials. The system features a set of electrodes half the size of Lincoln's head on a penny. Its translating hardware and software are able to find electrical signals from firing neurons and turn these into commands for computer cursors, light switches, or even prosthetics. Leigh Hochberg, M.D., Ph.D., of the Boston area company, Cyberkinetics Neurotechnology Systems, Inc., who is also on the faculties of Brown University and Harvard University, plans to recruit another ALS patient soon to the clinical trial.

Besides in ALS, another pilot clinical study is underway in people with other reasons for paralysis. Dozens of motor cortex cells have performed under the electrodes, sending signals that severely disabled patients could modulate to gain control over computer cursors, simple communication software, a prosthetic hand, and a simple jointed robotic arm.



Hope for ALS Patients

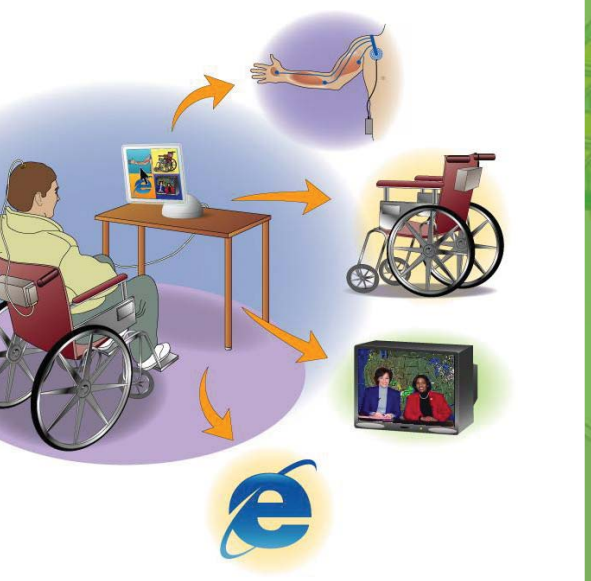
"While researchers continue to search for therapies to significantly slow the disease, there is still a tremendous need for new technologies that can help improve the lives of people living with ALS," said Lucie Bruijn, Ph.D., science director and vice president for The ALS Association. "The recent advances with brain interface technologies give us hope that it is possible to develop a technology that will be easy to use and that can restore a sense of independence and improved quality of life for many people who are unable to move or talk."

The instant ability to find and translate activity remaining in the motor cortex despite the years that have passed after this first ALS participant's diagnosis encourages Hochberg and others in the ALS field. The brain remains functional enough to promise eventual progress in prosthetic aids for people in quite advanced stages.

"It is encouraging to see that some of the same cortical signals which originally were used to control the arm can still be used by this trial participant to control a computer cursor," says Hochberg. "I'm encouraged that these types of signals might be harnessed by people with ALS to communicate more easily and to gain better control of their environment."

Indeed, in the field of brain-computer interfacing, experts say that it is ALS patients who are most likely to use and gain the best advantage from this technology.

By Roberta Friedman, Ph.D.
Staff Writer



Basic Research Bears Fruit

Hochberg began his work translating brain signals while an undergraduate, training monkeys who had been fitted with electrodes that showed changes in their neural activity as they moved a joystick to get a treat. Hochberg and collaborators built a software decoder that correlated patterns of neuron firing with the position of the limb. The signals from those cells then became the trigger for delivery of the reward. Soon the monkeys figured out they did not have to move and learned to simply think about the limb movement in order to gain the sweet treat.

Hochberg worked with John Donoghue, Ph.D., of Brown, who went on to found the company to develop the technology. They are lucky enough to get to see a project that began as basic curiosity about how the brain works translate in their lifetimes into the clinic to help people in need.

Hardware and Software

The electrode array sits over the part of the motor cortex that controls the hand. As with the monkeys, cortical activity could be transcribed and turned into signals that the very first participants have learned to vary simply by thinking about the cursor moving on the computer screen—just like the monkeys. In all human cases, control over the cursor has been achieved within the first day of experience with the equipment. The researchers with the project have already improved the decoding of the brain signals, Hochberg said in an interview at the fall 2006 meeting of the Society for Neuroscience in Atlanta, where he presented the results and a video of the ALS patient working with the system.

The software is adjusted each day with the ultimate goal to one day make the system work by telemetry, without the need for wires. The hardware is left in the patient's home and a technician comes to work out what can be accomplished with the system.

Many Assistive Devices

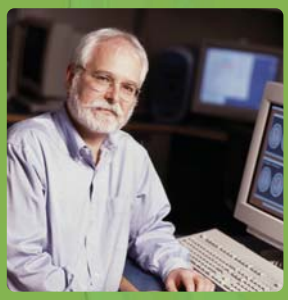
ALS patients are already able to take advantage of the electronic aids that already exist. These include portable keyboards that can generate speech or spell words when keyed by finger or by a joystick or even the flick of a forehead muscle, whatever movement remains. There are also non-invasive options for brain computer interfacing that do not require surgery thus avoiding the risk of infection and other complications. This involves faint cortical potentials collected at the scalp. However, training a patient to generate cursor movement through these scalp electrodes is much more time-consuming and prone to more frustrating error.

Some investigators have even produced communication, at least temporarily, from a completely "locked-in" patient by means of the change in the acidity of the saliva when asked to imagine the taste of lemon or of milk. Scholarly articles are written these days in research journals about "breaking the silence" of such patients, those who have absolutely no way to move or speak to indicate their thoughts or desires. These debates include the ethical questions of breaching the locked-in state, even as advances in medical technology generate that state more often.

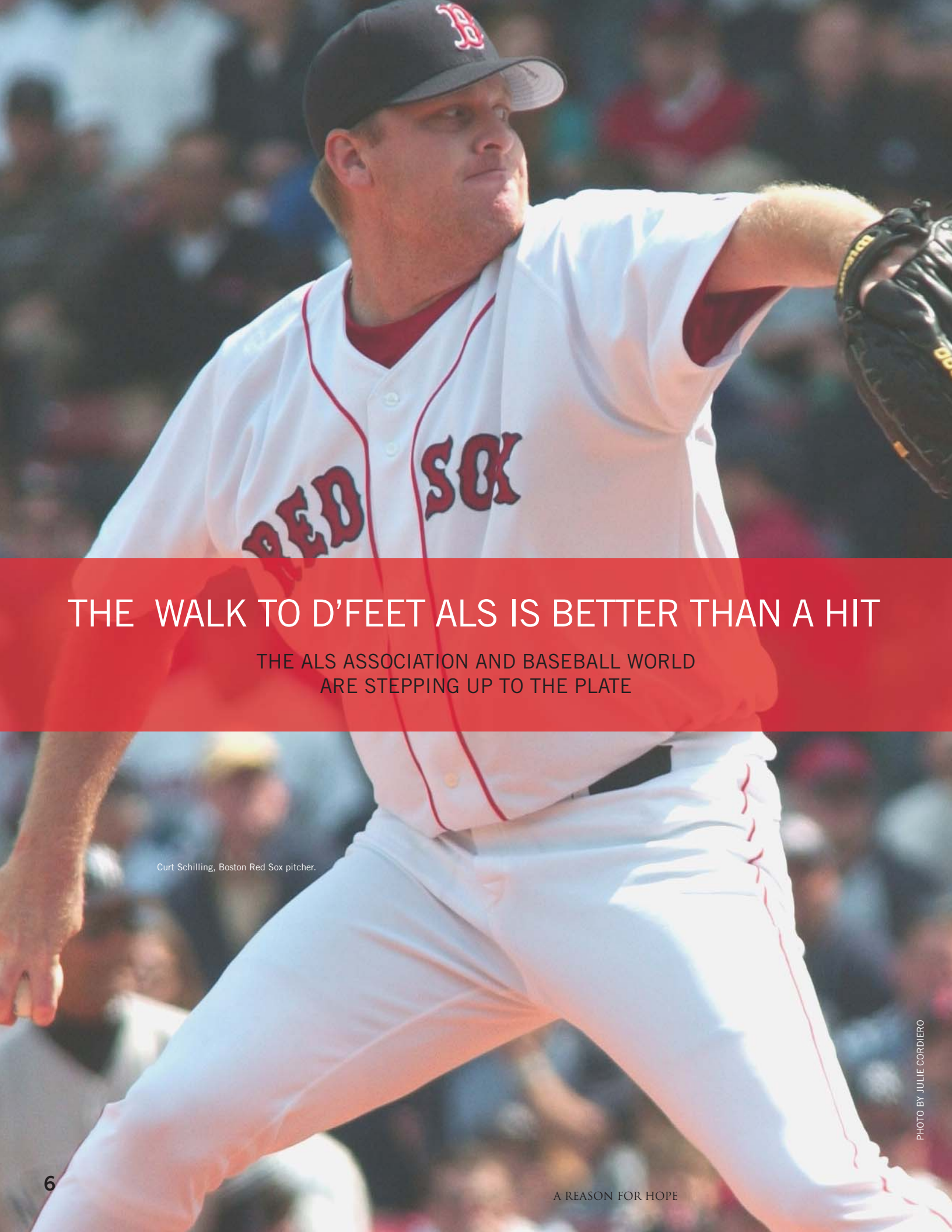
Ethical questions include how the availability of even the most rudimentary forms of brain computer interfacing might play into decisions about whether or not to opt for mechanical ventilation as ALS advances. Some experts propose that the means must be established to maintain communication before a person becomes completely locked-in, to retain a person's ability to learn the communication. Others say it should be offered only after the decision is made to accept mechanical breathing, to avoid influencing decisions about continuing life support.

Such arguments may or may not be important to patients who know they are losing their motor abilities. BrainGate promises the potential to keep ALS patients active participants in life, controlling their environments, communicating by voice activation and by email, and even playing computer games with their families. Stephen Heywood, the first courageous patient volunteer, kept that hope until he passed away in December 2006.

Leigh Hochberg



John Donoghue



THE WALK TO D'FEET ALS IS BETTER THAN A HIT

THE ALS ASSOCIATION AND BASEBALL WORLD ARE STEPPING UP TO THE PLATE

Curt Schilling, Boston Red Sox pitcher.

PHOTO BY JULIE CORDIERO

By Gary Wosk
Staff Writer

When people with ALS hear the umpire exclaim "Ball Four!" this season at Minor League Baseball stadiums, it will remind many of The ALS Association's national signature event, the Walk to D'Feet ALS®.

That is because they again will participate in the Walk in or near baseballl stadiums across the country.

Minor League Baseball's decision to host more Walks sponsored by The Association's national network of chapters last season and this season was as natural as the relationship between the two organizations. The seedlings of that bond came about in 1939 when legendary Lou Gehrig of the New York Yankees was diagnosed with ALS.

In those 68 years, the cause of fighting ALS and America's favorite past-time have gone together like a steamed hot dog slathered in mustard and topped by sauerkraut or chili.

The more than two-decades-old relationship between the league and The Association was strengthened in 2004 when The Association was invited to join the league's new Charity Partners Program. More than half of the teams and chapters participate in the program.

"The big money last season came from the Walk," said Nancy Venner, a community services director for The Association. "Walks in the stadiums attract more people."

The baseball Walks are indicative of a growing relationship, and with the debut of the pilot program "The K's for a Cure Club" – fans pledge money based on each strikeout recorded – the new season promises to be even more successful.

"Every year there is a little more being done," said Boston Red Sox pitcher Curt Schilling. "More people are aware of ALS. There is more chapter-community involvement and Minor League Baseball is a very big part of it. There is an enormous amount of potential for baseball, both the Minor and Major leagues, to raise awareness."

The increasing play-by-play between The Association and baseball is a relatively recent phenomenon. "Nothing like this has ever been done before," said Ray Robinson, the author of "Iron Horse: Lou Gehrig in his Time," many other books and a member of the Greater New York Chapter's Board of Trustees.

The Piedmont-Triad Walk in North Carolina was moved from a local high school track in 2004 to the roads surrounding Ernie Shore Field, home of the Winston-Salem Warthogs. The change in scenery worked wonders.

"Ballparks are family places where people come to relax and have a good time," said Megan Gardner, executive director of the Jim "Catfish" Hunter Chapter in North Carolina. "With the ALS connection to baseball, this seemed to be a natural fit."

By "passing the plate" during games, millions of dollars have been raised for services, programs and research. ALS and Lou Gehrig events at the ballpark, silent/live auctions and autograph parties and giveaways are among some of the other stadium activities held by the league.

THE BOX SCORE DOES NOT TELL THE WHOLE STORY.

"When a person and a family with ALS goes to a baseball game or event that is connected to The ALS Association it provides hope," said Ellyn Phillips, national trustee and president of the Greater Philadelphia Chapter's Board of Directors. "They think, 'Wow, everyone here is working to help me, and I don't even know them!' ALS can be such a lonely disease, but when you are in a crowd with everyone working toward the same goal...dollars for ALS, you feel like 'one of the gang'.. both empowered and proud."

As the new season unfolds, stadiums across America are being transformed into "Fields of Hope."

"Both parties are committed to going into extra innings if need be to find a cure for ALS," said Gary A. Leo, the president and CEO of The Association. "The bond between the two of us is a natural, and the mutual benefits are as exciting as a homerun."

TEAMS ALSO HAVE EARNED THE RESPECT OF FANS.

"Lou Gehrig being taken from the game by ALS has forever planted the awareness within the baseball community of the need for all of us to do our part combating the illness and seeking a cure," said Mike Moore, the president of Minor League Baseball. "Winning against ALS is far more important than any victory on the field."

The ALS Association's new chapter in South Carolina was very pleased with its inaugural season with the Charleston RiverDogs and Greenville Drive.

"It means a lot to people with ALS and their families," said Rebecca Jordan, the executive director of the South Carolina chapter. "They are excited that they are not alone. They do not want to see other people with ALS, but there is a comfort in being around people who know what it is like having the disease."

Major League Baseball teams involved in the fight against ALS include the New York Yankees, Boston Red Sox, Philadelphia Phillies, Minnesota Twins and the San Diego

Tommy John and Kent Hrbeck

Cal Ripkin, who broke Lou Gehrig's record with the number of games played in a row, with Joe Sample

Yogi Berra

Padres. Former and present Major League Baseball greats such as Schilling, Tommy John, George Brett, Cal Ripken Jr., Kent Hrbek, David Cone, Lou Piniella, Mike Timlin and Yogi Berra have been at the top of their game as ALS advocates.

It was fate that brought the "Bronx Bombers" and the ALS community together.

"No team has won more World Series than the New York Yankees; however, what makes the New York Yankees true champions in the hearts and minds of people with ALS is its commitment to raising awareness about ALS," said Dorine Gordon, national trustee and president of the Greater New York Chapter.

Tommy John and his wife Sally became involved in the fight against ALS when his friend and New York Yankees teammate, Jim "Catfish" Hunter, was diagnosed with ALS. John said Hunter asked him along with such other former Major League ballplayers as Sal Bando, Ron Davis and Mike Hershberger to come in from the bullpen when he was gone because "he knew he would not be able to go the full innings" and beat the disease.

Tommy and Sally John and their son, Taylor, travel for The Association and on behalf of the Greater New York and Greater Philadelphia Chapters and the Jim "Catfish" Hunter Chapter in North Carolina, which can be a golf tournament, an awards dinner, baseball clinic or testifying before Congress. At every event, they are sure to bring up Hunter and Gehrig. Because of his stature as a celebrity, Tommy John unabashedly admits people are more apt to listen to his message.

"Whether it is ALS or cancer, or any number of diseases, you need to have a vehicle to get your message out," said John, who played in the Major Leagues for 26 years. "I just happened to play a game that I was very good at and people will listen to what I have to say."

Because John said Hunter and Gehrig were arguably two of the best ballplayers to ever play the game and for perhaps the greatest franchise, the New York Yankees, he believes the relationship between The Association and with the world of baseball "is a perfect tie."

One of John's most rewarding experiences as an advocate was when he spoke about ALS before children and adults at the Conejo Valley Little League in Thousand Oaks, Calif., on behalf of the Greater Los Angeles Chapter.

He talked about how Hunter, his friend and teammate, was a "big, robust man and how his wife had to do everything for him later on. It was sad."

"Maybe a few of the kids will listen…when you're 10-, 11- or 12-years-old, all you want to do is play and to go Dairy Queen after the game," John said. "It is the parents who I really expect to pay attention, and it is my hope that some will volunteer for the chapter, or do something for the Walk."

There are other reasons John feels it is important for players, such as himself, to talk about the battle waged against ALS by Hunter and Gehrig.

"When I coached in 'Triple A' three years ago, the players did not even know who Johnny Carson was let alone Jim and Lou Gehrig or even Jackie Robinson. That's just the era of the game…not to say it's a good or bad thing. This is not a slam on the current players," John said. "There are so many ways to fill in idle time these days. They just are not students of the game like the players of my generation were. That's just the way it is."

"It's important for them to know how ALS devastated the lives of Jim and Lou, how fortunate they are to be playing in a sport that pays a tremendous amount of money and that there are people out there who will never have that opportunity."

KENT HRBEK HELPED START THE MINNESOTA CHAPTER OF THE ASSOCIATION.

"When people say ALS and Minnesota, people know what they're talking about," said Hrbek, formerly of the Minnesota Twins. "They understand what ALS is not only because of my involvement but also because of my wife Jeanie's and the Minnesota Twins, who are getting the word out."

Ellyn Phillips was not sure the chapter's first event with the Phillies in 1989 would go well.

"What if no one came?" she worried. "The entire organization, including all the Phillies players and wives, were so giving of their time; however, I had no need to worry about the outcome."

Channel 4 San Diego sports reporter and Emmy-Award winning producer and anchor Jane Mitchell, also the board chair of the Greater San Diego Chapter, helped build the relationship with the San Diego Padres.

San Diego Padre Scott Linebrink and his wife Kelly were the honorary Walk chairs and appeared at the Walk kick-off luncheon. Also, the couple was interviewed on the radio about the Walk, and their names were used for publicity purposes.

"We have been able to take the efforts of a wonderful group of people at the chapter to the next level because of the stage baseball provides," Mitchell said. "Having a relationship with a Minor League or Major League Baseball team helps you tell our story in very special ways that you may not be able to do without them."

Schilling said the experience has benefited him, his wife Shonda and their family as human beings and even his won-lost record.

"Out there on the field, you begin to wear down and then start thinking about the plight of people with ALS and you realize, 'You know what? Fatigue is really more mental than it is physical.'"

FOR MORE INFORMATION ABOUT THE WALK TO D'FEET ALS, VISIT http://www.alsa.org/walk/default.cfm.

By Patrick Wildman
Staff Writer

ADVOCATES PREPARE TO "March AND Roll" TO CAPITOL HILL

ALS Association
Fighting Lou Gehrig's Disease
National ALS Advocacy Day

Advocates from across the country are set to "March and Roll" to Capitol Hill this May as The ALS Association hosts the 10th Annual National ALS Advocacy Day and Public Policy Conference.

The three day conference, which takes place May 14-16, in Washington, D.C., provides the ALS community with an opportunity to join together, share their experiences and hopes, and urge Congress to join the fight against Lou Gehrig's Disease. Most recently, The Association helped to pass legislation in 2006 authorizing $290 million in funding for respite care. These are just a few of the accomplishments achieved by the thousands of advocates who have attended Advocacy Day during the previous ten years.

During the past decade, the advocacy conference has grown to become the single largest gathering of the entire ALS community, including people with ALS, families, caregivers, physicians, researchers, and many others whose lives have been touched by ALS. From Alaska to Alabama, Maine to Montana, advocates young and old come from across the country to tell the ALS story and let Members of Congress know the true nature of the disease and its devastating impact on families, on communities and on the nation. But that is only part of the advocacy experience. If you ask different people what part of the Advocacy Conference they find most rewarding, you'll likely get a different response every time. That's because there are so many memorable moments.

For many, the candlelight vigil, which this year will be held on the steps of the Jefferson Memorial, is the emotional highlight of the conference. Hundreds of advocates light candles under the evening sky in tribute to those who have lost their fight against this disease and sending the message that The ALS Association – people with ALS and their families – are lighting the way for a treatment and cure.

Others find reward in the educational breakout sessions which arm attendees with the tools and information they need to continue to make a difference throughout the year. And still others find Advocacy Day on the Hill to be the most satisfying, for this is the day when advocates march and roll, in wheelchairs and with walkers, to Capitol Hill and tell the ALS story to Members of Congress. It is an empowering opportunity. It is an opportunity for people with ALS and their loved ones to fight back – to play an active role in the advocacy efforts that can and do make a difference.

The accomplishments achieved as a result of Advocacy Day are evident. A 255% increase in annual federal funding for ALS research, from $15 million to more than $53 million; enactment of legislation to waive the 24-month Medicare waiting period for people disabled with ALS – the only time Congress has waived the waiting period since it was first implemented; and $1 million in Congressional funding to establish the building blocks for the first ever national ALS Registry at the Centers for Disease Control and Prevention (CDC). Most recently, The Association helped to pass legislation in 2006 authorizing $290 million in funding for respite care. These are just a few of the accomplishments achieved by the thousands of advocates who have attended Advocacy Day during the previous ten years.

Even with all of these remarkable elements of the conference, many find deeper meaning in their experience: to carry the message; to continue the fight for those whose lives have been cut short by ALS; and to light the way for a treatment and cure so that no one will ever again know the horror of this disease.

Join The ALS Association for the 2007 National ALS Advocacy Day and Public Policy Conference. To register to attend the conference, please visit www.alsa.org/policy/alsday.cfm. Additional information is available on the site, including a conference schedule as well as photographs and videos that show why the Advocacy Conference is such a powerful and rewarding experience for all who attend.

TO REGISTER TO ATTEND THE CONFERENCE, PLEASE VISIT
http://www.alsa.org/policy/alsday.cfm.

By Daniel Gonzales
Staff Writer

For nearly 30 years, Larry Barnett has been a pillar of strength and dedication for the thousands of people living with ALS.

Barnett first witnessed the devastating effects of ALS when a close friend's wife was diagnosed with the disease in the late 1970s. "I didn't realize it was going to be so difficult to conquer this disease," recalled Barnett of taking up the monumental task of helping to find a cure for ALS.

Recently, it has been Barnett who is grieving the loss of a loved one. His wife and best friend, Isabel Bigley Barnett, passed away in September 2006. Their partnership with The ALS Association over the years led to the establishment of The Association's inaugural post-doctoral fellowship, the "Lawrence and Isabel Barnett Post-Doctoral Fellowship for Research."

Barnett's compassion for those living with ALS has garnered him the distinction of being known as the "Grandfather of The ALS Association." The instrumental role he played in creating The ALS Association in 1985 was a crucial step forward in the fight against Lou Gehrig's Disease.

The Grandfather OF THE ALS ASSOCIATION

Larry Barnett

"When I think of the 30,000 patients in this country and Larry's 30 years of service to ALS patients and the families, I know there are millions of people who know that Larry and Isabel made an impact in this world," remarked The ALS Association's Chairman, Allen Finkelstein at a dinner honoring Barnett in November 2005. That night, Barnett was inducted into The ALS Association's "Circles of Giving" and received the program's highest honor, the "Circle of Life" Award.

After accepting the award, Barnett shocked everyone in attendance with a gesture of unselfish generosity for which he is known. He presented his long-time friend and ALS Association co-founder, Bob Abendroth, chairman of the Research Committee, with a check for $1 million dollars to support The Association's global ALS research program.

"I wanted to give away some of the successes I've had in life," said Barnett. "I've always wanted to be able to look back at my life and say that I've done something for other people." Barnett set the bar high because he understood early on the importance of finding a cure for ALS. His unforgettable mark on the ALS community will be revered for years to come.

Isabel Bigley Barnett: In Memoriam

Isabel Bigley Barnett was a loving and giving woman whose passion for life characterized her award-winning performances on the Broadway stage. Isabel passed away in September. Like her husband Larry, Isabel was firmly committed to helping those individuals living with ALS and ultimately finding new treatments and a cure.

After the Barnetts were married in 1953, Isabel moved from the stage to television and appeared with such notables as Dean Martin, Jerry Lewis, and Abbott and Costello. She eventually retired from show business in 1958 to raise her family. She once said that her family had been one of her greatest and most proud accomplishments.

As one might expect, Isabel Barnett cared immensely about the arts and many charitable organizations in addition to The ALS Association. She was heavily involved with the MaCallum Theatre in Palm Desert, serving as the first woman chair of its Board of Directors. Also, Larry and Isabel Barnett established a graduate program and fellowship fund in arts policy and administration reflecting their extensive commitment to Ohio State University.

"Isabel's passing is a tremendous loss for all of us," said Gary Leo, The ALS Association's president and CEO. "She was a unique woman who enjoyed a remarkable career in entertainment on the stage and then eclipsed that achievement through her lifelong commitment to philanthropy and personal devotion to family."

Larry and Isabel Barnett

By Daniel Gonzales
Staff Writer

A Family's Quest to Stop a Killer

Imagine living each day uncertain if there is a hidden killer lurking within your body. Imagine that this killer has already taken the lives of other family members and is casting a shadow over your children and grandchildren's future. Now imagine stepping out of the shadows and into the warm embrace of hope.

This is reality for Larry and Madelon Rand.

Larry and Madelon were married in the summer of 1964. Madelon's father, Allan, liked Larry tremendously and saw a lot of potential in him. Larry was equally as fond of Allan and loved him like a father. Things couldn't have been more perfect for the happy newlyweds and their family, until Allan started having difficulties walking.

Allan Leventhal

"My father began to have problems with his big toe and started to trip over himself," explains Madelon as she recalled her father's first encounter with ALS or Lou Gehrig's Disease. In 1965, Allan was officially diagnosed with ALS, but there wasn't an organization in existence dedicated to fighting the disease. The family received some support and equipment from other neurological organizations until Allan passed away in 1968. From that point on, Larry, Madelon, and Madelon's sister, Rochelle Moss, became heavily involved with the fight against ALS.

In 1985, Larry helped in the merger of the National ALS Foundation and the ALS Society of America, becoming Vice Chairman and a Trustee of the newly formed ALS Association. He later served as Chairman of the Board from 1987 to 1992. During these formative years, Larry faced three major obstacles with The ALS Association that he and the other national trustees managed to overcome. "We needed financial stability in the form of substantial fundraising. We also had to fund cutting-edge research projects by encouraging 'out of the box' thinking researchers, and develop a nationwide network of chapters to establish local patient outreach and support," explains Larry. "When I stepped down as chairman, the momentum and direction we established gained traction."

In addition to Larry's personal involvement and commitment, Rochelle was a founding member and executive director of The National ALS Foundation. She worked tirelessly to find a cure for ALS until she was also diagnosed with the disease in the late 1990s. However, unlike her father, Rochelle developed a relatively rare form of ALS with frontotemporal dementia (FTD), which causes a change in personality and mental processes. "She started having trouble making complex decisions before she had any physical symptoms of ALS," recalled Madelon. "I always admired my sister. She was my best friend, and her death was a great loss to me and our entire family."

Rochelle Moss

When Rochelle passed away in 2002, Larry and Madelon realized that familial ALS was present on Madelon's side of the family and that they had to stop this unforgiving killer. "Who knows what genes my children or grandchildren are carrying. I want to get rid of this disease once and for all," explains Larry, who, with Madelon, decided to strengthen their commitment to The ALS Association by establishing **The Lawrence and Madelon Rand Frontotemporal Dementia in ALS Research Fund** to help uncover the mystery of ALS with FTD.

"My dream is to find a cure for ALS," states Larry. "We cannot stop funding research because that next dollar might be the critical one that enables scientists to eradicate this disease forever." It is that kind of strength and determination that could, one day, make Larry and Madelon's dream of a world without ALS a reality. Just imagine the possibility.

Larry and Madelon Rand

By Katie Sweeney

Marsh Douthat in power wheelchair with lift chair, manual chair and portable respirator

Living With ALS

ADAPTING YOUR HOME TO ALS

Tom and Claudia Garafola's two-story house in Gaithersburg, Md., served them well for two decades.

Rolling floor lift

Wheelchair accessable shower

But in 2002, Tom was diagnosed with ALS. And when he lost his ability to walk two years ago, they realized it was time to make some changes to their longtime home.

One problem: Many rooms had been built with a step-up or step-down to enter or exit it. To bridge these steps, the Garafolas installed custom-made ramps throughout the house. Their neighbor, a contractor who had built their house, volunteered to design the ramps, and a cabinet-maker custom-made them for free.

"They look great, and they function very well," Claudia says. "People don't even notice the ramps anymore. Our house looks normal."

Like the Garafolas, many people with ALS make home renovations—both major and minor—to suit their changing needs. But deciding which modifications to make and which home equipment to add isn't easy, and not everyone is lucky enough to have a handy neighbor or relative.

"The ALS Association's role is to educate people in terms of what their options are," explains Sharon Matland, R.N., M.B.A., vice president of patient services for The ALS Association. "It doesn't have to be high-cost. We work with families to help them identify the best solutions for their specific situation."

Many Association chapters also "recycle" adaptive equipment among families. In addition to walkers, computers and wheelchairs, many chapters loan out home equipment such as ceiling lifts and stair glides if they become available.

For Jack Parker, who was diagnosed with ALS in 2002, that loaner system saved him money and prevented him from undertaking a major bathroom remodel. The Association's Georgia Chapter loaned him a Guldmann ceiling lift system that takes him directly from his bed to the toilet, tub or wheelchair.

"I thought we were going to have to take the tub out and install a roll-in shower," says Jack, 70. "With this system, all we had to do was widen the doorway."

How do you decide which renovations and equipment make the most sense? Robin Swope, L.C.S.W., patient services clinical director for the DC/MD/VA Chapter, advises families to consider their resources and the amount of time and energy, not just money, it will take to complete renovations. Another factor to consider: How quickly is the disease progressing?

"You have to think about whether there will be time to complete the renovations and really use them," Swope stresses. "You also have to think about whether those renovations are going to increase or decrease the value of your home."

Many times, an extreme home makeover isn't the answer. Instead of adding on a room, many families turn the dining room or other downstairs area into a bedroom, with a portable commode and privacy screening. Sometimes doing a sponge bath makes more sense than adding a roll-in shower.

For Tom Garafola, installing a stair glide has meant that he can still sleep in his own bed every night. But for people with weak trunk muscles, stair glides often don't work well, Swope explains. And there needs to be plenty of room to safely transfer the person to a wheelchair at the top of the stairs.

"Everyone's different," she says. "There's no one-size-fits-all."

The best advice? If possible, try to anticipate your needs a few months in advance, so you have time to research and plan. And don't go it alone. Talk to other people with ALS and, just as important, contact your local Association chapter for assistance.

"I've learned so much just by talking to other people with ALS," Jack Parker says. "The best thing we can do is help each other."

Your Legacy of Hope...

A Century of Memories

Laura McCrum

Sidney McCrum

Laura McCrum celebrated her 101st birthday this year.

Born in 1906 in New York, Laura has experienced a century of memories.

Laura has lived through two world wars, the Korean War, Vietnam, the Persian Gulf War, and now the war in Iraq. She has experienced the Roaring 20s, the Great Depression, the New Deal, man walk on the moon, the fall of the Berlin Wall, and Y2K. She has lived through eighteen presidencies, starting with Theodore Roosevelt. She has seen the invention of talking pictures, television and the Internet. During her lifetime, many diseases have been cured or greatly eliminated – except for the one she most wishes had a cure: ALS.

"It's a horrible disease," Laura says. "I hope they find a cure. I hope not many more people have to suffer."

One of Laura's favorite memories is the day she met her husband, Sidney. "My friend had set a date with Sidney, but then, made a date with another wealthier gentleman whom she liked better. So she asked me to go to Sidney, make an excuse and break the date," recalls Laura. "That's when we first met."

One of her most painful memories is the day Sidney was diagnosed with ALS some 30 years ago, well before The ALS Association came into existence. Laura and Sidney sought help from one of The Association's predecessor organizations, The ALS Society of America (ALSOA). The McCrums befriended one of ALSOA's leaders, who had ALS himself. "We met this wonderful man in a wheelchair and his wife at a luncheon," remembers Laura. "Through him, we were able to locate a nurse to help me with Sidney."

Sidney was "a very good patient," according to Laura. "He never complained." He was cared for at home almost the entire duration of his illness. His last two years were spent in bed. Laura placed Sidney's bed near the window of their fifth floor apartment. "He enjoyed the view of the city," she remembers fondly.

Sidney died in March of 1980. He and Laura had been married 43 years.

It was shortly after his death that Laura decided to honor Sidney by making a gift to The ALS Association through her will. "As soon as he died, I made up my mind," Laura says.

To learn more about making a bequest to The ALS Association, contact Juan Ros, Director, Gift Planning, at (888) 949-2577, ext. 212, or via e-mail: juan@alsa-national.org. You can also visit The Association's gift planning web site at www.alsa.org/giftplanning.

To receive information in the mail, complete and mail the coupon below. All inquiries will be strictly confidential.

"It was my idea, and I did it because of Sidney."

Sidney and Laura had no children, so it was a fairly simple matter to add a bequest to The Association in Laura's will. Laura was welcomed as a charter member of The Lou Gehrig Legacy Society in 1996.

Would Laura recommend others include The Association in their estate plans? "Certainly I recommend others do it," she answers, "so that we can find a cure!"

Although scientists still know very little about ALS, the progress of research has accelerated in the last decade, thanks to advances in technology and the generosity of individuals who have chosen to leave a legacy of hope to The ALS Association – like Laura McCrum.

"I know I won't see a cure in my lifetime," Laura acknowledges, "but that doesn't matter. I did it for Sidney, to honor his memory" – the most precious memory she has from the last 101 years.

Attention: Office of Gift Planning

- ❑ I am interested in learning more about charitable gift annuities. Please contact me.
- ❑ I would consider remembering The ALS Association in my will, trust or other estate plan.
- ❑ I have already remembered The ALS Association in my will, trust or other estate plan.

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Mail the completed form to: Director of Gift Planning,
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