A REASON FOR

# HOPE

THE ALS ASSOCIATION

FALL 2005

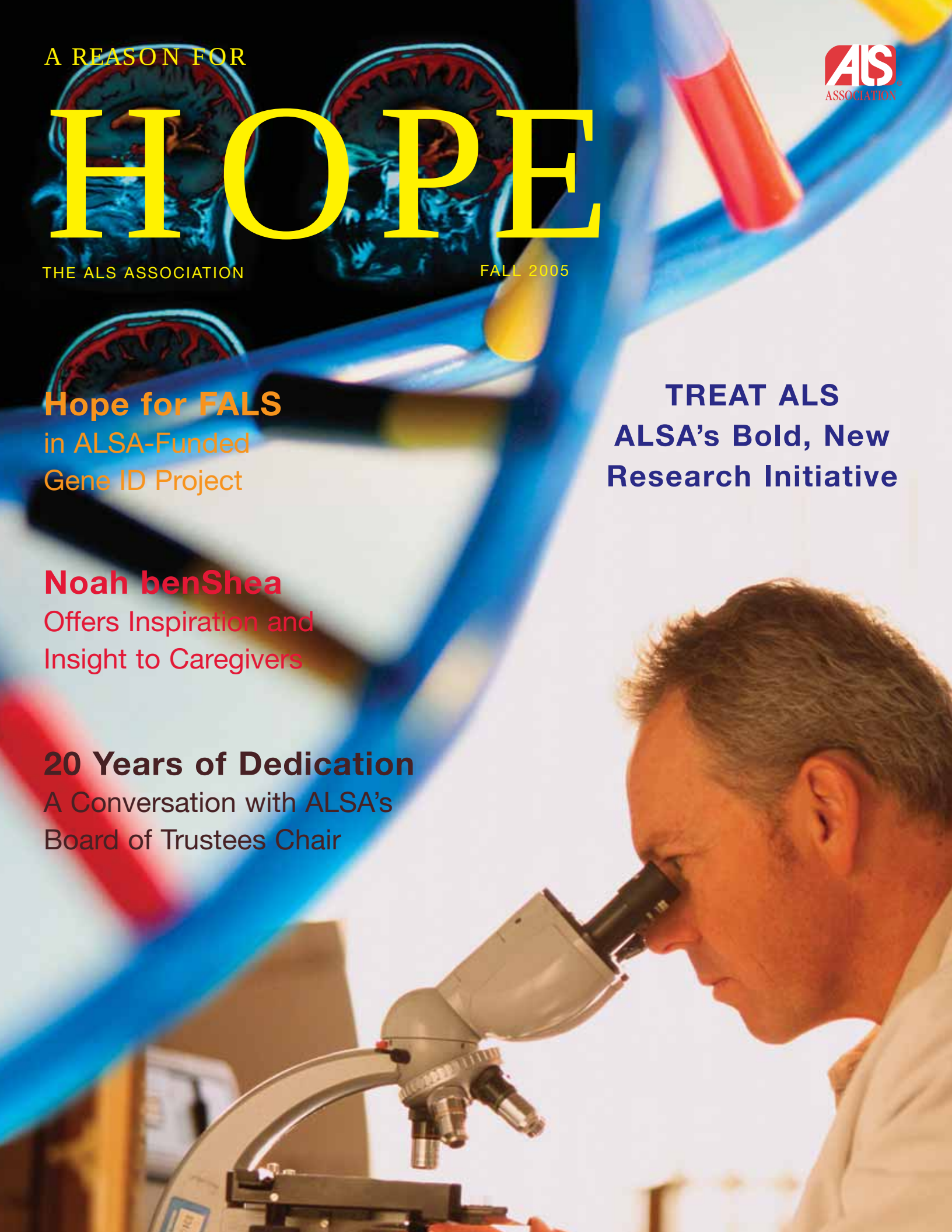
ALS ASSOCIATION

**Hope for FALS**
in ALSA-Funded
Gene ID Project

**TREAT ALS**
**ALSA's Bold, New**
**Research Initiative**

**Noah benShea**
Offers Inspiration and
Insight to Caregivers

**20 Years of Dedication**
A Conversation with ALSA's
Board of Trustees Chair



A REASON FOR

# HOPE

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**ABOUT THIS ISSUE...** A Reason For HOPE is The ALS Association's flagship publication, and we hope you find it a useful way to learn about advances in research, patient services and advocacy efforts as well as feature articles about people in the ALS community. This issue focuses on research initiatives, ALSA's leadership and caregivers.

TREAT ALS (Translational Research Advancing Therapy for ALS), is a bold, new drug and treatment discovery initiative to direct leading scientists toward developing drugs to halt or significantly slow the course of ALS within the next ten years.

In an interview with Allen Finkelstein, ALSA's National Board of Trustees Chair, we discuss ALSA's 20-year history, how The Association evolved from two parent organizations and the source of ALSA's strength.

Noah benShea, ALSA's National Laureate, delivers an emotionally charged message to those who are in supportive love of those who have ALS. The author says, "ALS, I have decided, is a heavenly sent acronym reminding us to Always Love Someone. And ALSA, I have come to know, is a gathering of caring people whose day-to-day work and commitment to Always Love Someone Always may seem heaven sent, particularly in the face of those who, in their inevitable isolation, are too often feeling heaven abandoned."

HOPE visited with Alan Griffith, one of the people responsible for helping to establish The ALS Association and making sure the ALSA maintains its focus on providing the best in patient care and finding a cure for Lou Gehrig's disease.

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.

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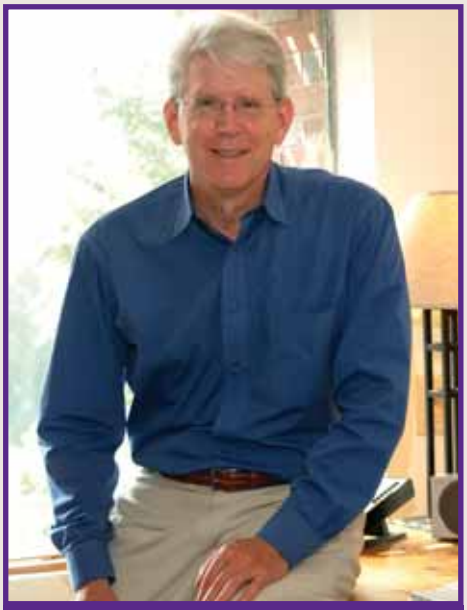
# VISIONARY SCIENTIST

## Drawn to ALS Research

*By Roberta Friedman, Ph.D., ALSA Research Department Information Coordinator*



Tom Maniatis

Tom Maniatis, Ph.D., is a molecular biologist adept at manipulating DNA, but he was as little versed in the details of the nervous system and how it is destroyed by amyotrophic lateral sclerosis as anyone else when his sister became ill in the late 1990s. Like anyone else, Maniatis had to search around for help in finding out exactly what was happening to her. Through this personal connection with the disease, Maniatis was drawn into a dedicated effort to help find a cause and effective treatment for ALS. For the past five years, he has served on the scientific advisory board for The ALS Association and has shaped ALSA's new initiative, Translational Research Advancing Therapy for ALS (TREAT ALS), to accelerate drug discovery and entry into clinical testing.

"I certainly was not knowledgeable regarding the course of the disease, but I learned very quickly," says Maniatis, who is Thomas H. Lee Professor of Molecular and Cellular Biology at Harvard University. He noted that the ALSA web site was an important source of information for his introduction into the disorder.

His sister was in the advanced stages of her disease when ALSA National Trustee Robert Abendroth approached him to become part of the ALSA steering committee to guide research into the cause and effective treatment for ALS. Since that contact, impressive progress has been achieved. ALSA funded research has produced new model organisms that recreate features of ALS. Study of mice engineered to express the human SOD1 mutation meanwhile demonstrated that the surrounding, supportive cells of the nervous system can affect how the motor neurons live or die. Ongoing still is a massive effort to sequence the DNA from families with newly discovered mutations linked to the disease. Without ALSA recruiting and organizing top geneticists in the field, Maniatis says, this project wouldn't have happened.

> "I have a lot of experience developing drugs. I hope to bring that know how to this steering committee."

What Maniatis hopes to achieve through TREAT ALS is an end run around the fact that the root cause of ALS remains unknown. There are a lot of compounds that already exist or are on the drawing board, he says, that deserve careful study to see if they could help in ALS.

Maniatis brings to ALSA not only his background as a successful academic researcher but also his credentials as a successful entrepreneur. He has started three biotech companies that have taken basic research into how genes work and translated that knowledge rapidly into effective new therapeutics. Maniatis recalls when he set up his lab at Harvard in 1980, "I had never really thought about working with a company and that things done in my lab would have an impact on diseases that I could see. It affected how I thought about problems such as ALS," he says. "I have a lot of experience developing drugs. I hope to bring that know how to this steering committee."

Maniatis' expertise is in cloning, which is the ability to copy genes and produce in the lab the proteins they specify in copious amounts. His personal experience with ALS did not produce an immediate change in his research directions. "I felt I could contribute more by being on the ALSA committee," he says, finding and guiding other experts in the field to take on ALS.

But he has been tilting towards recruiting young investigators with experience in the nervous system and has begun collaborations with others working in directions that could lead to investigations into the basic nature of ALS. Now Maniatis is ready to take on basic questions of how the disease operates. "I am feeling more comfortable in that area." He is enthusiastic about his new approaches, and ALSA is set to build on a decade of progress with his continued commitment.

Maniatis with Ben tenOever, Ph.D., postdoctoral fellow and Entela Nako, research assistant

# ALSA Launches New Program to Accelerate Drug Discovery and Clinical Trials

*By Roberta Friedman, Ph.D., ALSA Research Department Information Coordinator, with Janet Young, Manager, ALSA Project Development*

The ALS Association has launched a groundbreaking initiative concentrating effort towards rapid discovery of new therapeutics for amyotrophic lateral sclerosis. TREAT ALS (Translational Research Advancing Therapy for ALS), a program to provide more rapid clinical testing, is the most comprehensive effort ever undertaken to focus leading scientists on developing one or more drugs within the next decade that will prevent, halt or significantly slow the course of this devastating disorder.

TREAT ALS prioritizes existing drugs for clinical trials in order to start those trials as soon as possible. Treat ALS also takes on the task of drug discovery to find new compounds with promise for the disease.

This program has not yet opened any specific clinical trial, but the process is underway to have the necessary framework in place once new candidates are identified.

Existing drugs meanwhile may be able to help patients with ALS.

## Progress

Researchers have made tremendous advances in the ALS field. We understand far more about the biological basis of the disease process. This knowledge has enabled the design of laboratory models that have yielded innovative ideas and clinical candidates.

- Strides have been made towards finding biomarkers, signals in the body that show the disease is developing or progressing.
- New therapeutic strategies show encouraging promise, including stem cell and gene silencing techniques, which are poised to take on ALS even as the science behind these techniques continues to develop.
- Genes are being discovered that control how motor neurons form, live, and die.
- Existing medicines may have aspects that will aid in treating ALS, according to evidence building from cell based screening tests.

The time is, therefore, right to translate these concrete advances into effective therapeutics for ALS patients.

## Urgency

TREAT ALS adds a new, urgent dimension to the innovative granting program carried out by The ALS Association. The groundwork has been laid, and a steering committee of experts from industry, federal agencies, and academia is in place and dedicated to TREAT ALS.

"Our ultimate goal is to capitalize on scientific and technological progress to accelerate drug discovery and realize effective new therapy," says Lucie Bruijn, Ph.D., ALSA science director and vice president. "We understand far more about the biological basis of the disease. Now tangible progress will be turned towards patients to produce treatment success."

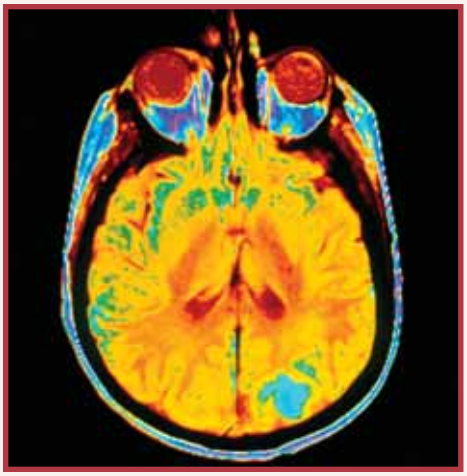
## Groundbreaking Advances

Over the last decade, The ALS Association has committed more than $30 million to ALS research. Currently, ALSA is funding more than 120 ALS research studies worldwide.

A decade ago, researchers found that a mutated gene, SOD1, is responsible for 20 percent of all familial ALS cases. Though only directly relevant for a few percent of ALS patients, this crack in the ice encasing the mystery of the disease led swiftly to a mouse model that closely mimics ALS in all patients and gives researchers vital information about the biology of the disease process.

## Key Genes and Stem Cells

A concerted ALSA-initiated effort is now underway to identify more genes that



play a role in ALS. This Gene Identification Project involves some of the most prominent experts in the human genome project as well as ALS experts.

Meanwhile, researchers supported by ALSA funds have published their discovery of key genes that govern the ability of developing brain cells to connect properly to the spinal cord, providing scientists new insights for repair of the damage seen in ALS. This follows on the heels of studies showing that human stem cells can be made to become motor neurons, the cells of the nervous system destroyed by ALS.

The evidence is building that stem cells may be a viable means towards effective treatment of ALS. Another promising route to treating ALS is with gene therapy delivering supportive factors to threatened motor neurons. This gene therapy achieved initial success in mice, with animals bearing the SOD1 mutation living a bit longer as published this year.

## New Technologies and Existing Therapeutics

Other strategies are equally compelling. For instance, this year three independent research teams, some with ALSA support, showed that SOD1 mice injected with a gene silencing therapeutic displayed improved motor skills and an increase in survival from the time of diagnosis.

Existing drugs meanwhile may be able to help patients with ALS. A collaborative effort between ALSA, the National Institutes of Health, and several academic research labs found that a class of antibiotics share a property unrelated to killing bacteria that helps support the survival of motor neurons. This important result gathered from cells growing in lab dishes has slated one of the drugs, ceftriaxone, for testing in clinical trials.

## Better Drug Trials

Clinical trials could more quickly determine that a treatment will help ALS patients if the onset and progress of the disease were easier to identify. Diagnosis of ALS is notably difficult and is often delayed by the insidious beginnings of symptoms that mimic other conditions. A collaborative effort sponsored and funded by ALSA is underway to find biomarkers of ALS to aid trials and to improve diagnosis.

Biomarkers are the biological signature of a process or disease that scientists can detect in the bloodstream or even in other body fluids. A sample of fluid can show the presence of molecules that reflect altered metabolism or toxic byproducts in a disease process. Modern techniques can find just a few molecules in very small amounts of fluid.

A collaborative effort sponsored and funded by ALSA is underway to find biomarkers of ALS to aid trials and to improve diagnosis.

ALSA has also funded research that allows researchers to more easily see changes in motor performance in rodents modeling the disease. Mutant mice that recreate the symptoms of ALS in the laboratory due to the mutant SOD1 gene display an early, subtle change in their walking gait detected by a new gait analysis computer system that should help investigators more rapidly identify promising new treatments for ALS.

If early testing can demonstrate a drug's promise, corporate interest is more likely to be engaged.

## TREAT ALS - The Next Step in ALS Research

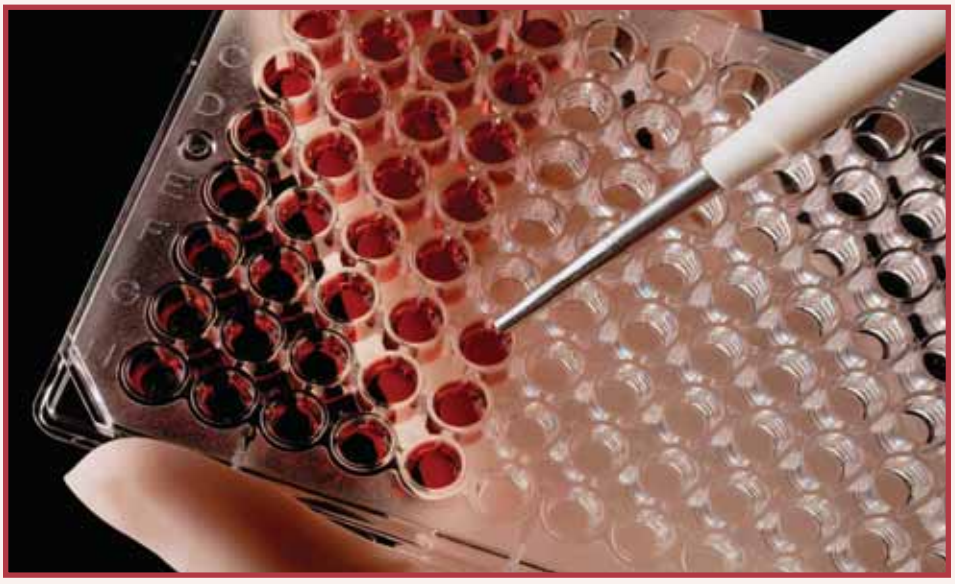
TREAT ALS is geared to develop one or two leading compounds, which can be ready for large-scale clinical trials within five years. This means the identification of small molecules that demonstrate activity in animal models of ALS and an acceptable safety profile for evaluation in a Phase I clinical trial. At the same time, ALSA seeks to engage in one or two small pilot trials each year of known or existing compounds.

ALSA plans to select and solicit laboratory models of the disease, which can be used to screen large numbers of compounds that are available in so called "libraries." Cell-based assays are essentially basic aspects of ALS reflected in cells growing in dishes. The more relevant the assay to ALS, the more likely it will identify potentially effective drug candidates.

Those compounds that appear to be the most promising in the dish will be selected for testing in animal models of ALS. This pre-clinical work supported by TREAT ALS will lay a foundation for pharmaceutical company sponsorships of large clinical trials, which can cost millions of dollars. If early testing can demonstrate a drug's promise, corporate interest is more likely to be engaged.

As with the drug development track, the infrastructure of the focused clinical trials program through TREAT ALS will ensure trials are effectively run, and patients are enrolled in a timely manner. Better-designed clinical trials will provide new methods to detect real change in patients through biomarkers.

TREAT ALS will enable further support of those efforts most likely to develop promising leads for ALS. TREAT ALS will consolidate these efforts, launch from them a series of clinical trials, and will translate a decade of progress into real promise for ALS patients.



# Every Family

## Is Touched by ALS, but Some More Than Others

*By Dan Gordon*

Martin Silva, Jr.

When Martin Silva Jr. was just 11, he watched his father begin a five-year decline culminating in death at age 47 from undetermined causes. "He would fall down, and he would take a long time to eat, often choking himself," recalls Silva, 56, who lives with his wife, Ana, in the Rio Grande Valley of south Texas. "Now we think it was that disease."

That disease is ALS. Silva came to the realization that it was the culprit in his father's death the hard way. A little more than a decade ago, ALS took the life of Silva's brother, Roberto. In 2001, Silva began to experience some of the same symptoms that he had seen in his father and brother. After a lifetime of good health – in 30 years as a carpenter and painter, Silva never missed a day of work – he began suffering from arm and leg cramps. He became wobbly, constantly stepping on his wife's feet on their regular nights out dancing. In 2002, Silva was diagnosed with ALS.

Nine out of 10 times, ALS is not inherited. Silva falls into the smaller category of approximately 10% of patients with familial ALS (FALS) – passed from one generation to the next. "For these families, the disease can be quite common – we have seen some in which up to 30 family members are known to have had ALS," says Jennifer Brand, M.P.H., director of patient services for The ALS Association.

Understandably, once they hear that the disease could be inherited, many ALS patients and their family members become extremely concerned, Brand notes. "But it's rare for someone who has the first known case in his or her family to have the inherited form," she explains. "Much more typically, someone who has FALS will have several close relatives who have also been diagnosed."

The most common known cause of FALS is a mutation in a gene located on chromosome 21 called Cu/Zn superoxide dismutase (SOD1). This mutation, which is believed to cause cells to make a defective SOD1 protein that is toxic to motor nerve cells, is most often inherited in an autosomal dominant fashion, meaning that a child born to someone with the SOD1 mutation has a 50% chance of inheriting the FALS gene. FALS family members can be genetically tested to determine whether the SOD1 mutation has been passed on. For these families, pre-symptomatic genetic testing is a highly personal decision. Absent strategies to prevent the disease, a positive test does not change treatment, nor does it predict the age at which the carrier will get ALS – or even whether he or she definitely will. FALS family members considering pre-symptomatic testing may want to discuss the issues with a genetic counselor.

> Typically, someone who has FALS will have several close relatives who have also been diagnosed.

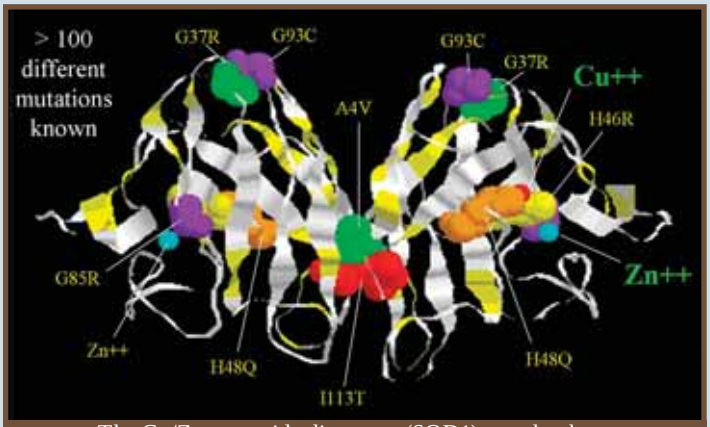
Moreover, since SOD1 accounts for only about 20% of the familial cases, a normal SOD1 test result is not informative in a family in which an SOD1 change hasn't been identified. Researchers are continuing to search for the genes that are involved in causing the disease in the other 80% of FALS families.

In an unprecedented familial ALS research effort, ALSA awarded its largest research grant to date to the Gene Identification Project, which uses technology derived from the Human Genome Project to identify the mutations and genes linked to ALS by employing large-scale DNA sequencing. This unique project brings together an international consortium of researchers, who are searching for new genes involved with ALS linked to chromosomes 16 and 18. "Finding new genes will enable us to piece together the puzzle of ALS to understand how the disease works and develop drugs to target the disease," said Lucie Bruijn, Ph.D., science director and vice president of The ALS Association.

> Silva began to experience some of the same symptoms that he had seen in his father and brother.

Since 1984, investigators at Northwestern University's Neuromuscular Disorders Program have collected blood samples from more than 660 families for genetic studies of familial ALS; approximately three-fourths of these FALS families do not have the SOD1 mutation, according to Nailah Siddique, R.N., M.S.N., clinical nurse specialist working on the study. "The flaw with many genetic studies is that they are a snapshot in time, but we stay in touch with our families because we need to know what happens," explains Siddique.

"Linkage analysis" studies performed on large non-SOD1 FALS families are enabling the Northwestern researchers to look for other genetic causes, says Siddique, who notes that the team has



The Cu/Zn superzide dismutase (SOD1) gene has been identified with about 20%of FALS cases.

pinpointed several chromosomal areas of interest and is homing in on specific genetic culprits. Linkage analysis studies compare the DNA of affected family members to look for similarities within particular chromosomal regions and to see whether the genetic makeup at these sites is different for the unaffected family members. For more information on the study or to inquire about participation, contact Nailah Siddique at 312-503-2712.

From a research perspective, FALS can provide important insights into the disease by enabling investigators to home in on the genetic causes, says Dr. Bruijn. "Sporadic disease may also have a genetic component, but more than one gene could be involved, or the gene involved may be a risk factor that causes the disease only in combination with environmental contributors," she says. Because the clinical presentation of the familial and sporadic forms is similar, the hope is that what is learned from familial ALS will be applicable for all forms of disease. Although this has not been proven, Dr. Bruijn notes, "so it is possible that we need to look more carefully by using biomarkers to determine whether the familial and sporadic diseases have some unique features."

Finding new genes will enable us to piece together the puzzle of ALS.

Researchers have developed a mouse model with the same genetic change as occurs in SOD1 familial ALS cases and are using it to better understand how this mutation can lead to symptoms of ALS, as well as to test therapies to slow or halt the disease's progression. "Mutant SOD1, linked to 20% of FALS, has opened the field and suggested an approach for therapy by a new technology, RNA inhibition," Dr. Bruijn says. This so-called gene-silencing approach prevents a specific gene from making its protein. Targeting the SOD1 enzyme, researchers at the University of California, San Diego recently reported that mice with the SOD1 mutation show better grip strength if treated with the RNA therapeutic.

At Emory University in Atlanta, Georgia, researchers at The ALS Center are recruiting healthy members of FALS families for participation in a potential clinical trial aimed at testing compounds intended to prevent or delay the onset of ALS in these at-risk individuals. Many drugs have been effective in the SOD1 mouse. These same compounds have not proved to be effective when tested in humans with ALS. Since clinical trials are conducted in people with sporadic ALS, the Emory researchers, led by Jonathan Glass, M.D., the center's director, are pursuing the theory that sporadic and familial ALS, though they appear the same clinically, have different mechanisms, and that drugs that improve disease outcomes in SOD1 mice might also be effective in preventing or delaying the onset of ALS in people with the SOD1 mutation, even if they are not effective in clinical trials involving sporadic patients.

The Emory researchers have received hundreds of telephone calls from family members interested in participating and have created a database that includes more than 2,000 people from FALS families. "The response has been extraordinary," Dr. Glass reports.

These and other research efforts provide some measure of hope to families like Martin Silva's. More than three years after being diagnosed with ALS, Silva worries about other family members – a younger brother, six daughters and a son, 21 grandchildren, and two great-grandchildren. "It's hard to know if they're going to get it," he says, his voice heavy with concern. "You just don't know."

Mice with the SOD1 mutation show better grip strength if treated with the RNA therapeutic.

- Approximately 5-10% of persons with ALS have a close second family member with the disease, referred to as familial ALS (FALS).
- The remaining 90% of cases are isolated (not directly inherited in a family), also known as sporadic ALS.
- There are no known differences in the symptoms of familial and sporadic ALS. The best tool to distinguish between familial and sporadic ALS is the family history.
- The most common known cause of FALS is a mutation in a gene located on chromosome #21 called Cu/Zn superoxide dismutase (SOD1). This mutation, which is believed to cause cells to make a defective SOD1 protein that is toxic to motor nerve cells, is most often inherited in an autosomal dominant fashion, meaning that a child born to someone with the SOD1 mutation has a 50% chance of inheriting the FALS gene.

# ALSA – Twenty Years of Dedication

## A conversation with ALSA's Board of Trustees Chair

*Allen L. Finkelstein is a partner in the Law Firm of Ganfer and Shore, LLP based in New York City and has been involved in the fight against ALS for more than thirty years. He holds a BS in Business Administration with a minor in Economics from New York University, a JD from Brooklyn Law School, and an MBA from Long Island University. In addition, he has been an adjunct associate professor of business administration at Long Island University.*

HOPE: This year marks ALSA's 20th year as an organization. As a founding member of the Board of Trustees, how has ALSA evolved over the last two decades?

FINKELSTEIN: Two decades ago there were two ALS groups, one on the East Coast: the National ALS Foundation and one on the West Coast: the ALS Society of America. While both professed to be national organizations, they were probably not significantly more than regional organizations. The sum of the parts being greater than the separate parts, the two organizations merged with the help of several members of our Board of Trustees. Since then, we've grown from a merged organization with between $2 million and $3 million in revenue to an organization, which is a $30 million institution. The opportunities for one organization with 40 chapters nationwide is far greater in providing services to the entire ALS community: patients, families, caregivers and the medical practitioners.

Allen Finkelstein at the 2005 Leadership Conference in St. Louis

HOPE: How did you become involved with Lou Gehrig's disease and ALSA?

FINKELSTEIN: I used to respond that I exited on the wrong subway stop. But the truth be known, over thirty years ago I was asked to draft the charter for the National ALS Foundation. One winter evening I went to the home of the Kossmans who lived in Brooklyn. Bill Kossman had been diagnosed with ALS, and he and his wife Debbie had discovered there was no organization in existence to provide support and information to them. So their only choice was to start one. At first, I never dreamed I'd do anything more than establish a corporate entity for this not-for-profit organization. But, I ultimately concluded that this clearly was the right spot for me. No one was providing the services that were so crucially needed. Although, I now have relationships with many people living with ALS, thank God, nobody in my family has ever had ALS. I am merely giving back some of the benefits that I have had growing up as a first-generation American.

HOPE: ALSA has a very active Board of Trustees. How would you describe the board and what its role is in furthering ALSA's mission?

FINKELSTEIN: The board is composed of dedicated, inspired and hard-working individuals including patients, caregivers, business people and professionals – all working harmoniously to find the cause and cure for this tragic disease. I have been and still am involved with many charities. Not one of them has a board that is more dedicated and more productive than the one that we have. Each individual contributes at an amazing level. It has been an evolutionary process. The boards of the two original organizations were quite different. Great foresight was demonstrated when these people gathered in the same room – people like Larry Barnett, Bob Lotz, Bob Abendroth, Larry Rand, Morton Charlestein, who is Ellyn Phillips' father, Arthur Levein, and Steve Ross, just to name a very few. Ego didn't play a role here. The driving force was the will to do something positive and to try to help people with the disease. And nobody can argue with our success.

"I have been and still am involved with many charities. Not one of them has a board that is more dedicated and more productive than the one that we have. Each individual contributes at an amazing level."

HOPE: Describe the strength and unique qualities of ALSA in the fight against ALS.

FINKELSTEIN: In the United States, ALS, unfortunately, afflicts some 30,000 people. You can't compare it to AIDS, heart disease

Allen Finkelstein, John Cook, executive director of business operations for Minor League Baseball and Gary Leo, ALSA's president and CEO

or to cancer, which affect much larger numbers. ALS is an orphan disease. When you compare the results of what 30,000 patients can accomplish, which is, at this point in excess of $30 million a year, our fundraising is enviable. It's as good as there is out there. Our support of cutting-edge research is world-respected, and the patient services we provide – it's incredible. Our ability to raise funds for research and patient services – and balance the two – that makes us unique.

HOPE: ALSA has a nationwide network of chapters, centers, and clinics providing front-line services. What is their impact on the ALS community?

FINKELSTEIN: A phrase I often hear is, "I don't know what our family would have done without ALSA." And I think that says it all. Frequently, families know nothing of ALS, although they've heard of Lou Gehrig's disease. And then, unfortunately, a member of the family is diagnosed with ALS. Physicians know to direct patients to ALSA for support. And, we provide extraordinary patient and caregiver services. ALSA's Certified Centers, clinics, and our network of chapters are all working at 100 percent of capacity to provide services. If we were able to raise $40 million or $50 million or $100 million a year, we would be working, in relative terms, at a higher capacity. So it's a function of ALSA's community: the chapters, the centers, the boards, the clinics, all working at full capacity, that will achieve the success to have the kind of impact that will find the cause and cure. A criminal attorney, and occasional professional adversary, heard of my involvement with ALS. And he said, "Allen, you're not going to believe this, but I have a client who is being released from jail because she has ALS. She has no family or money, and she doesn't know what she's going to do after she's released." So, I called a local chapter and said, "You need to do me a favor and help this poor woman out." The chapter took care of everything. This is a woman who had no money or family. She was a person with ALS who needed help. The chapter said, "We will take care of her."

HOPE: Do you feel that science could be on the threshold of some significant discoveries in ALS research?

FINKELSTEIN: Well, I'm frequently asked that question, and the answer that I generally give is, "I don't know whether we're two hours away, two days away, two weeks, two months or two years. But we will succeed." We have made significant progress, and I do believe we are at the cusp of success. The projects and researchers our organization is sponsoring have made incredible strides over the last twenty years. I'm convinced we are approaching the point where, by dint of hard work or accident or a combination of the two, we will succeed.

HOPE: What was research like in the earlier day?

FINKELSTEIN: What we saw twenty and thirty years ago were alleged researchers, alleged doctors, alleged clinics that were treating patients with snake venom and professing to have success. It was all hocus-pocus. Today, we're seeing very solid, experienced researchers at major institutions throughout our country and the world, which we are supporting, all of which are doing research in a fashion that eliminates things that we shouldn't be looking at and pursuing that which we should be looking into.

HOPE: ALSA's message is about hope. How do you describe the way ALSA delivers hope to people with ALS, their families and caregivers?

"Join me in this sojourn and succeed with the sole objective of relegating ALS to a footnote in medical history and closing the doors of our Association, having eliminated the disease."

FINKELSTEIN: Webster defines "hope" as the feeling that what is wanted can be had, or that events will turn out for the best." There's a secondary definition: "To look forward to with desire and reasonable confidence." Delivering hope is the charge of our professional staff. I'm only a shepherd. And you guys are doing the hard work. And that's why patients and caregivers have come to rely you.

HOPE: How do you envision ALSA's future? How do you see ALSA in about five years?

FINKELSTEIN: Looking into my crystal ball, ALSA is at the center of the ALS universe and continues to be the source and the resource for this universe. Our centers, our clinics, and our research will be the standard. Can you imagine if we were able to effectively treat even a third of our patients, prolong their lives, give them a legitimate basis to believe that they can live a relatively, if not completely, normal life. Do I have a scientific basis for this hope, for this belief? I don't. It's this crystal ball I'm looking into. But I do know that our hard-working chapters, our clinics, our centers, our board of trustees and our professional staff will persevere and succeed. Most organizations have an objective to grow. That's not my objective. It's my objective to find the cause and the cure, to treat the remaining patients, to help their caregivers and their families close our doors as a result of the services that we have provided and will continue to provide to eliminate the ALS universe. And I ask all of you who are reading this interview to join me in this sojourn and succeed with the sole objective of relegating ALS to a footnote in medical history and closing the doors of our Association, having eliminated the disease.

A phrase I often hear is, "I don't know what our family would have done without ALSA."

# The Best Way to Find an Angel Is to Be One

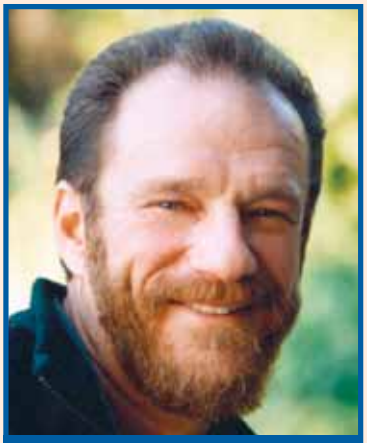
*By Noah benShea, ALSA's National Laureate*

When my father was formally diagnosed with ALS, I didn't think of it as a diagnosis. This was a word for polite company, and there was nothing polite about this diagnosis because to me this was not a diagnosis - it was a sentence. And while the sentence fell on my father, all of us in the family also began serving time. We began serving time because time no longer served us. We now had a limited time with my father because he had limited time. And the clock ticking under all of our lives suddenly was ticking more loudly.

The way my family tried to turn down the sound of this ticking is with denial. For almost all of us who are confronted with ALS, denial is the first drug of choice. What we don't want to face is often the first face we put on when the inevitable is in our face.

"Far more critical than what we know or don't know," said the Philosopher Eric Hofer, "is what we do not want to know."

The day we had to take the door off my parent's bedroom so my father's wheel chair could get through, my mother cried. A month later her crying grew into a wail. Eventually every wall in my parent's home became the wailing wall.



Noah benShea

Around this same time, I remember seeing in my own kitchen, a cartoon strip pinned to the refrigerator door with letters from a magnetic alphabet. The cartoon's first frame was of a woman who had grown exasperated while speaking with her ailing mother on the phone. The cartoon's last frame is of the woman's husband asking his wife if she notices that she now speaks to her parents and her children in the same voice. "Well," demands the wife, "what does that mean?" "It means, don't die," answers the husband. "Everyone is counting on you!"

If someone you love or care for has ALS, then sooner or later, you will come to the realization that maybe not everyone but someone, for sure, is counting on you. And the person or persons who are also counting on you is not just the person with ALS. And lastly, the last person you expect to count on you and better count on you is YOU! Because without you, you can do zero, nothing, squat, zippo, nada, niente.

benShea and ALSA President & CEO Gary Leo at 2005 Leadership Conference

Being supportive to others does not mean being superior to anyone. It does require us to be superior to our previous self. And this takes all the courage in the world. And this is the battle of bravery to which some of us have enlisted and some of us will be conscripted by caring.

When someone you love or care for is struck down with ALS, you, the caregiver, are wounded collaterally. The caregiver wakes up wounded, and goes to work wounded, and comes home wounded, and eats dinner wounded, and lies in bed staring at the ceiling trying to go to sleep wounded, and stands wounded at parties, and hears glasses tinkling, and people laughing. And then one day it dawns on you, that the great players play injured, play wounded, play on. And that is your red badge of courage.

When someone you love or care for is stricken with ALS, you may find yourself for the first time praying if only praying for answers. The novelist Erica Jong writes, "There are no atheists on turbulent air flights." And she's right. But let me tell you sister, you have never been on a rocky flight until you're living with ALS or living with someone who has ALS. We're talking turbulence at a whole new altitude. On Trans Faith ALS Airlines only the angels have wings. And the best way to find an angel is to be one.

When someone you love or care for is stricken with ALS, you discover a sense of humor, because if you can't laugh, some part of you dies – a little sooner – a little harder – a little more alone. The song says laugh and the world laughs with you. Oh yeah, well let me tell you about how off-key that is with ALS. When you have ALS, there comes a time that when you laugh or cry, it doesn't mean you are laughing or crying. It simply means you are emoting and have no other

way to express emotion. When someone with ALS laughs, all you know is that they're feeling, and what they're feeling when they're laughing could very much be something to weep over.

As my father lay dying, I needed to be in the sorrow of that moment. When I came home from the hospital and my kids jumped in my arms, I needed to be there in that moment's joy. It takes courage in life to be congruent with the moment - every moment - and to come with integrity to every moment.

People who don't have ALS have as much right to and as much need for our love and caring as those who do. Yes, our time with those with ALS is limited, but who can presume to know how much time we have with any of the people we love?

No one can presume to speak to the courage that it takes for any of us to deal with the day to day and make it through the day. The dignity of my father's blue-collar workday was seldom the work but dignity he brought to the work. My father's message remains unmistakable and relevant: Bring dignity to what you do, and your work will bring dignity to you.

The recognition that matters most in life is self-recognition. If you are playing a support role to someone struggling for their life, honor yourself for who you are and how you conduct yourself. Of all the things you could make in life, remember you are making a difference.

In the middle of life's struggles there inevitably comes a time in each of our lives when we collapse and turn to the heavens demanding to know why this is happening, swearing we can't take another step. This experience is often accompanied by a good cry and a fair amount of self-pity. Nevertheless, like you, I have learned that when the pity party is over, there is little to be done but to stand up, straighten our back, and put one foot in front of the other. In this effort is our shared humanity. Strength is not the absence of weakness but how we wrestle with our weaknesses. The average child will fall three hundred times before he or she learns to walk.

The courage of every day living isn't often talked about because it doesn't usually have a press agent. The courage of every day living is often heroism in private. Often, even we don't see the courage of what we do as heroism. But that does not make it any less heroic.

Noah on his father Sidney Wiesblott's lap with his mother Harriet holding brother Lorne in 1949

It is 1990. I am in a hospital room. My father has just stopped breathing. I am shutting my father's eyes. The emotional wallpaper is a mix of relief, release, resignation, and remorse. Somewhere in the cosmos a door is shutting forever, even as another one opens. And the truth that is nailed to the door speaks in my father's mute voice and says this: Thank you for your caring. You made a difference. I know you were scared. And so was I. I know you were not in charge. Neither was I. Put aside your fear. I am on the other side.

A man was being shown around heaven and hell. In both there was a large table laden with food, and both sides of the tables were lined with people unable to bend their arms. The difference between heaven and hell was that in hell the people were trying to feed themselves and starving. And in heaven all the people had stretched their arms across the table and were feeding someone on the other side.

Caring for others is sacred work. And as with all things sacred, we are not expected to finish the work but neither are we excused from it.

Bless you.

Noah benShea



Left to right: Lorne, Harriet, Sidney and Noah in 1989 one year before Sidney's death from ALS.

Those wishing to contact Noah benShea can do so at his website www.NoahbenShea.com

# A TOWER OF STRENGTH
## for People Living with ALS

*By Michael Friedman*

It is easy to understand why people who have a friend or loved one with ALS care about the disease. The life and death struggle, the hope for treatments and a cure, the need for easier access to medical equipment, and the desire for a caring community, all conspire to keep you focused on the disease. But what makes a man who has no direct connection to ALS care enough about the disease to dedicate a lifetime of volunteer work to help the 25,000 to 30,000 Americans who are afflicted with Lou Gehrig's disease?

> "We all hope for a cure or therapies so we can prolong life and improve the quality of life for people living with ALS."

"What keeps me involved is the need to provide for the families of people living with ALS and to accelerate research to find a cure," says Alan Griffith, one of the founders and long time National Trustee of The ALS Association (ALSA) and member of ALSA's Greater New York Chapter Board of Trustees. "We all hope for a cure or therapies so we can prolong life and improve the quality of life for people living with ALS."

Alan R. Griffith

Griffith began working to benefit those with ALS in the late 1970s. At that time, he was a senior vice president of The Bank of New York and was asked by a friend to be treasurer of the New York-based National ALS Foundation. Griffith agreed, not realizing that he would still be involved three decades later.

Allen Finkelstein, another veteran ALSA National Trustee, who currently serves as the Nation Board of Trustees Chair, and close personal friend, offers this rationale for Griffith's dedication to volunteering. "Alan apparently comes from the same kind of family background that I come from, which is: if you are fortunate enough to have a degree of success in this world, you need to share that success. We both saw a vacuum 25 or 30 years ago; there was no organization that could help people with ALS. We thought it was something that we ought to be doing. There was a void that existed, and we tried to fill it – Alan far more than me."

In the mid 1980s, there were two main charitable organizations dedicated to fighting ALS. One was the National ALS Foundation; the other was the California-based ALS Society of America. Senator Jacob Javits of New York, who eventually succumbed to ALS, was among a group of people who believed that if either organization was to fully realize its goal of defeating the disease, they would have to join forces. In 1985, the National ALS Foundation merged with the ALS Society of America to become The ALS Association.

Griffith became a member of the Board of Trustees of the newly formed organization, and continued to work hard on behalf of people living with ALS. It was at a national board meeting that Griffith met Robert Abendroth, an ALSA Trustee who had been a part of the ALS Society of America. "I have the greatest respect for Alan's commitment to ALSA," says Abendroth. "He is one of the few board members who has no personal experience with ALS, yet has been a faithful contributor."

As the years passed, Griffith's resolve for The ALS Association grew. "It was such a compelling story to me. At the semi-annual board meetings, the commitment of the board members and the dedication and enthusiasm they had to the cause rubbed off on me," Griffith explains.

Griffith with baseball hall-of-famer Johnny Bench

In addition to his work as a National Trustee, in recent years Griffith focused much of his energy on ALSA's development efforts as chair of The Lou Gehrig Challenge Campaign. According to ALSA President and CEO Gary Leo, "Alan has been a driving force behind much of our fundraising efforts. And because of his dedication, ALSA has been able to fund the world's preeminent ALS research program for the past 20 years."

After a decade and a half of unwavering commitment to ALSA as a National Trustee, Griffith was given the opportunity to further solidify his link to The Association. Dorine Gordon's mother lost her battle to ALS in 1992. In response, two years later, Gordon founded the Greater New York Chapter of The ALS Association. "I immediately made an appointment to see Alan Griffith because he was a National Trustee from New York. I asked for his assistance in jumpstarting a New York-based chapter," recalls Gordon, an ALSA National Trustee who also serves as President of the Greater New York Chapter.

"We wanted to raise the visibility of the Greater New York Chapter," Griffith recalls. One idea that floated around was a fundraising dinner. "I thought that was something I could do." However, Gordon remembers the genesis differently. In her telling of the story, Griffith suggested holding a fundraising gala to kick off the founding of the chapter and now is simply too modest to take credit for a great idea.

Together, Griffith and Gordon planned and held the gala event, the first Annual Lou Gehrig Sports Awards Benefit, and it was a resounding success. As Gordon recalls, "Alan said, 'maybe we'll raise $250,000.' The first year we raised $500,000."

Eleven years later, the benefit is as successful as ever. Past honorees have included legends such as Muhammad Ali, Reggie Jackson, and Bob Costas. As Finkelstein aptly puts it, "it is one of the premier events in Manhattan – which probably has five to ten charitable events every night of the week. It is premier by any standard."

At this year's event, there will be a special honoree. On Tuesday, October 25, 2005, Alan Griffith will be presented with the Jacob Javits Lifetime Achievement Award. The Award, named after the Senator who two decades ago helped form The ALS Association, is in honor of Griffith's work on behalf of the Greater New York Chapter. In addition to his work in jumpstarting the chapter, Griffith will be honored for his years of service on the chapter's board and for serving as the chapter's chair. In his typically selfless way, Griffith recalls when Gordon asked him to be chairman, "I have such a high regard for Dorine that I agreed."

The Award comes at a pivotal point in Griffith's life. This past May, Griffith successfully oversaw the completion of ALSA's five year, intensive fundraising campaign called The Lou Gehrig Challenge with over $18 million raised. As the chairman of the Campaign Cabinet, much of the success of the Challenge can be attributed to Griffith's dedicated leadership. In addition, after 41 years with The Bank of New York, Griffith retired as Vice Chairman this past summer. Although relocating, Griffith plans to remain active with ALSA both nationally and with the Greater New York chapter.

This is not a surprise for Finkelstein who says, "If you go back over the history of The Association, there are certainly not more than two handfuls of people who have made the commitment to develop ALSA into a premier organization, and Alan is on that very short list. If you count the number of people on that list who are still active, the number is even less. He is arguably among the most generous people associated with ALSA in every manner – service, time, financially. Alan's dedication has been complete."

"The commitment of the board members and the dedication and enthusiasm they had to the cause rubbed off on me."

According to Abendroth, that kind of commitment from a man like Griffith is important. "When he speaks everyone listens. We at ALSA have been lucky to have him participate in our organization. On the national level, he's been invaluable. And, he has been a tower of strength for the Greater New York Chapter."

But for Griffith, his commitment is simpler than any of that. As he puts it, in his own modest way, "We want to see the organization provide support, help and comfort to people living with ALS."

As Leo says, "Alan's commitment, leadership and support for The ALS Association over the past two decades are excellent examples of why I am confident we will fulfill our mission to find a cure for ALS."

# LIVING WITH ALS
# I Am Still the Same Guy Inside

*By Katie Sweeney*

Eric Obermann wasn't the only patient to testify in front of a U.S. Senate committee on National ALS Advocacy Day this year. But there was one thing about him that immediately separated him from the others: his age.

Just 23 years old, Obermann has been living with ALS since he was 18. And while he describes himself as a quiet person who doesn't seek the limelight, he eagerly agreed to travel to Washington and tell his story to the Senate Appropriations Committee Subcommittee on Labor, Health and Human Services.

"I am so young, and I wanted to let Congress know that this disease affects people from all walks of life," he explains. "The current budget provides far too little funding for direct ALS research."

Pictured with Obermann are L to R: Roz Fellwock (grandmother), Lauren Obermann (sister), Stuart Obermann (father), Marcia Obermann (mother) and Janet Obermann (aunt)

Obermann's testimony, which he wrote himself, took place on May 11 in front of Sen. Richard Shelby of Alabama, who chaired the hearing, and Sens. Tom Harkin of Iowa and Patty Murray of Washington state. Obermann and other ALS advocates were joined by former Yankees pitchers Tommy John and David Cone and actress Kate Linder of "The Young and the Restless."

Although he cannot speak and is on a ventilator, Obermann testified via a speech synthesis computer that he operates with his right big toe. He began his story by describing his life in May 2000, before the first ALS symptoms appeared.

"I was a typical 18-year-old, excited to graduate from high school and a bit nervous about going to college," he told the committee. "I was a first chair clarinetist and enjoyed playing with the school marching band…Life was good, and my future looked great."

Obermann with The Young and the Restless star Kate Linder and former baseball pitcher Tommy John

But just as he was beginning his freshman year at Georgia Tech University, his ability to play the clarinet began to slip. Soon, he developed a speech impediment. His doctor referred him to a neurologist, who diagnosed him with ALS. His mother was with him.

Stuart and Eric Obermann during hearing on the Hill

"We just looked at each other, wondering what had happened to us," Obermann remembers. "We were in shock."

He went for second, third and fourth opinions. Because of his young age – the average age of ALS diagnosis is 55 – other specialists were reluctant to confirm the diagnosis. But there was no denying that his condition was progressing. In 2002, he had to drop out of Georgia Tech after contracting severe pneumonia. He went back to school that fall at the University of Alabama at Huntsville, his hometown, but eventually had to quit again, due to the disease's progression.

Still, Obermann refused to give up.

"Two things ALS cannot take from me are my mind and my spirit," he told the committee. "Despite the radical changes my body has undergone, I am still the same guy inside…I can travel with my family, go to movies and concerts, attend swim therapy and take walks in the woods. My family has dedicated themselves to helping me live with ALS rather than simply waiting to die from it."

One major source of strength for the Obermanns has been an ALS support group in Huntsville. Obermann's parents, Stuart and Marcia Obermann, decided to get more deeply involved and are now leading the group's efforts to become an ALS Association chapter. Stuart, who stepped down as CEO of an Internet technology company to help his son, is chairman of the board. Marcia, a registered nurse, heads up patient services.

Darin Kruse (PALS from Alabama), Eric and Marcia Obermann and Bud Cramer (D, 5th AL)

"We felt that we needed to turn some of our anger into positive energy," Marcia explains. "I've found that it helps me cope to help somebody else."

The trip to Washington was yet another way to do something positive to fight ALS. "This was an important thing for us to do," Stuart says. "It was a very exciting and gratifying experience."

Obermann's advice for ALS patients of all ages is simple: Don't lose hope. "Hang in there because there is real progress being made," he says. "Secondly, do the things you always wanted to do while you still can. Take charge of your life."

Eric Obermann's entire testimony can be read on ALSA's website. http://www.alsa.org/policy/article.cfm?id=661

# "IT IS OUR PERSONAL MISSION TO STAMP OUT ALS."

The Lou Gehrig Legacy Society

Lawrence R. Barnett, with wife Isabel.
Founding Chairman, The ALS Association,
Honorary Chairman,
The Lou Gehrig Legacy Society

*"I had never met anyone with ALS before I became involved. But in meeting patients and families, my wife and I have become very passionate about doing everything possible to find a cure for this disease. Now, we are leaving a legacy of hope with a gift in our estate plan. Please join us by doing the same."*

Join ALSA's Lou Gehrig Legacy Society by including ALSA in your will or trust, by making a life-income gift or other planned gift.

Contact Juan Ros, Director of Gift Planning,
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