Most Common Cause of ALS and FTD Identified

Researchers funded by The ALS Association have found a genetic abnormality that is the most common cause of amyotrophic lateral sclerosis (ALS) and frontotemporal dementia (FTD), accounting for as much as one-third of all familial ALS. As reported in the recent online issue of the scientific journal *Neuron*, an unusual mutation of a gene called C9ORF72 was discovered, where a short DNA sequence is repeated many more times in people with ALS when compared to healthy individuals.

The identification of this gene abnormality was independently made in two studies, one lead by Bryan J. Traynor, M.D., National Institute of Aging, and by a team at the Mayo Clinic in Florida, led by Rosa Rademakers, Ph.D. “This finding has the potential to lead to significant insights into how both of these neurodegenerative diseases develop and may give us much needed leads into new ways to treat our patients,” said Dr. Rademakers.

Investigators worldwide were committed to identifying this gene mutation, which until now had remained elusive. The defect is also the strongest genetic risk factor found to date for the more common, non-inherited, sporadic forms of these diseases.

“This is a phenomenal scientific finding—the first genetic link between ALS and FTD,” commented ALS Association Chief Scientist, Lucie Bruijn, Ph.D. “The more we understand the biology, the more clues we have, the more likely we can develop new therapeutic approaches.”

Please turn to page 6

Baseball Provides Ideal Venue for ALS Awareness Activities

By Stephanie Dufner

Each baseball season brings with it opportunities for ALS awareness. New York Yankee Lou Gehrig gave his name to the disease more than 70 years ago. Gehrig’s connection with America’s favorite past time has allowed The ALS Association and other ALS organizations to partner with both Major and Minor League Baseball teams throughout the season to tell fans about the impact Lou Gehrig’s Disease has on people in the ALS community.

Fans at the three inning Angels vs. Dodgers Legends Celebrity Softball Game and Home Run Exhibition. The Golden West and Orange County Chapters co-sponsored this July 3, 2011 event in Anaheim Stadium.

Events that The Association’s Chapters participated in from May through September included Major League Baseball’s 4 ALS initiative, which educates the public about this progressive, neurodegenerative disease and raises funds for research.
Longtime Trustees’ Expertise Helped The ALS Association to Flourish

By Stephanie Dufner

Three of The ALS Association’s longstanding leaders from its National Board of Trustees have recently retired. Alan Griffith, Ben Ohrenstein and Laural Winston each have served more than 20 years as volunteer leaders working to strengthen the effectiveness of The Association.

They also brought greater awareness of Lou Gehrig’s Disease to their communities by supporting their respective chapters.

“One of the things that Alan, Ben and Laural enhanced is our organization with a wide spectrum of talent and knowledge,” said The Association’s President and CEO Jane H. Gilbert. “We appreciate their dedicated service in working toward our ultimate goal of finding treatments and a cure for ALS.”

Alan Griffith—Advocate for Those Battling ALS

Alan Griffith became involved in the fight against ALS in the late 1970s and is one of The Association’s founders as he was serving as treasurer of the National ALS Foundation in New York City when it merged with its California-based counterpart, the ALS Society of America, in 1985 to form The ALS Association. Griffith’s desire to find resources for those fighting the disease and support research for treatments and a cure motivated him to share his business expertise while serving on several of the Association’s Board committees.

“Alan brought to The ALS Association a wealth of experience from his professional life and his membership on other not-for-profit boards,” said Bob Abendroth, a fellow founder and former board member. Abendroth worked with Griffith on three committees and stressed his colleague and friend always gave sound advice on managerial and budgetary matters.

Griffith’s fiscal acumen helped to design successful fundraising efforts such as the “Lou Gehrig Challenge Campaign: The Campaign to Cure ALS.” This national fundraising program sought contributions for ALS-specific research and gathered more than $18 million dollars under his guidance.

In addition to serving on the Board of Trustees, Griffith’s charity has also extended to The Association’s Greater New York Chapter. Dorine Gordon, one-time national trustee who serves as the chapter’s president and CEO, credits Griffith for much of the chapter’s growth since its inception in 1994.

“One of the reasons that the chapter has grown so significantly,” said Gordon, “is that Alan has been unwavering in his commitment to The ALS Association both at the national and local levels for more than 30 years.”

Benjamin S. Ohrenstein—Sound Financier and Dedicated Volunteer

Benjamin S. Ohrenstein is an accountant and lawyer, who prefers to be called Ben; he is quick to explain “Mr. Ohrenstein is my father.” He has generously given of his time and experience to grow The Association into a multi-million dollar enterprise to fight ALS. As a volunteer, he served as The Association’s Treasurer and Chief Financial Officer from 1995 to 2011, while operating Ohrenstein Law Offices in Haverford, Pennsylvania.

“I could not ask for a better friend, lawyer, accountant and dedicated volunteer for the Greater Philadelphia Chapter and the National organization,” said National Trustee Ellyn Phillips. “Ben achieved so much as The Association’s Treasurer and chair of the Board’s finance committee. In addition, he helped the chapter to grow from a mom-and-pop charity with $4,500 to the $5 million chapter it is today.”

Phillips met Ohrenstein and his wife Dottie in 1983 at an ALS support group that Phillips and her now-deceased husband, Alan, were attending. Ohrenstein joined the fight against Lou Gehrig’s Disease nearly three decades ago after Dottie’s cousin was diagnosed with the disease. He became a member of the National Board of Trustees in 1993 and lent his pecuniary wisdom to several of its committees, including investment, executive, and board operations.

Laural Winston—Leader in the Call for Compassionate Care

“Our organization’s services for people with ALS would not be in existence if it were not for Laural,” said National Trustee Stephen Saltzman. This describes the diligence and dedication Laural Winston has provided for patient care as well as for the organization’s mission of empowering people with Lou Gehrig’s Disease.

Winston’s interest in helping those with Lou Gehrig’s Disease stemmed from personal experience. Her aunt, Rubye Harmonson, died from ALS in 1987 after being diagnosed with the disease in late 1983. Harmonson’s experiences with ALS prompted Winston to establish the Orange County Chapter in 1984. She served as the chapter’s treasurer for the next 20 years,.setMaxPageLength(10)
Thanks to Shirley (Hoffman) Schmelzle, the ALS community now has a powerful and universal new awareness symbol: the sunflower.

In August of 2009, Schmelzle learned that she had amyotrophic lateral sclerosis (ALS). Thus far, Schmelzle remains physically active; however, the disease has taken away her ever-cheerful voice and has forced her to communicate only in writing. But as fierce a disease as ALS is, it has far from silenced her. “When I was first diagnosed with ALS, I was shattered,” she said. “But then I reached a point where I felt that I had to do something. I knew that I must help. And so I did some fundraising; I wrote some articles; I reached out to people; I researched; I enrolled in a Phase III clinical drug trial.”

“For people diagnosed with this disease,” she continued, “there is not that much time, frankly, to be an advocate. There are so many things tugging on your heart and purse strings.” Schmelzle explained that from the moment she became involved in advocating for ALS awareness, she was struck by the lack of a universal symbol for the fight against the disease. “There was no pink ribbon as with breast cancer, no red dress as with heart health,” she said. Schmelzle became convinced that having such a universal symbol would aid exponentially in advancing ALS awareness—and she soon learned that many others agreed.

For the last two years, Schmelzle has fought tirelessly to have the sunflower adopted as the universal symbol of hope for those living with ALS. She has worked closely with The ALS Association Central and Southern Ohio Chapter to develop the concept, engaged a graphic designer to craft an image to bring their ideas to life, run focus groups with the help of a marketing professional to further develop the concept, and has knocked on countless doors to push for broader adoption of the new symbol. She hopes that someday the sunflower will become the nation’s symbol of hope for those battling ALS.

“Schmelzle is a vibrant, positive can-do woman who, because of being diagnosed with ALS, has turned her energy, her skill, her experience, her connections and her get-it-done personality toward raising universal awareness of ALS,” said ALS Association Central and Southern Ohio Chapter Executive Director Marlin Seymour. “There are thousands of people across the country and the world who feel the same as Schmelzle about ALS—we want to help and support those who are suffering the effects that it brings, and we want to see an effective treatment or eradication in our lifetime.”

The symbol itself, created by Chicago-based artist Hayley Porst, features a trio of sunflowers reaching upwards toward the sun with the words “Defeat ALS” anchoring the image. It was designed to evoke a sense of hope, grace and dignity and to reflect the support that those living with ALS receive from family, friends and organizations such as The ALS Association.

Jane Gilbert, president and CEO of The ALS Association offered her support and said, “The ALS Association is excited to support the effort to make the sunflower the national symbol of ALS awareness. We hope that this new unified symbol will provide a simplified and consistent public image for ALS awareness, and we encourage other ALS organizations to join us in embracing the sunflower as the national symbol of hope in the battle against ALS.”

As a result of Schmelzle’s efforts, those who suffer from ALS, their families and supporters, the many organizations that advocate for and fund research to defeat ALS, and the community at-large will now have a common image that is easy to recognize and that is visually unifying.
to find the causes and a cure for Lou Gehrig’s Disease. In July, both the Chicago White Sox and Cleveland Indians respectively partnered with the Greater Chicago Chapter and Northern Ohio Chapter for this endeavor. Several chapters also partook in “Speak Out Against ALS,” a multi-media event created to raise ALS awareness with the combined participation of chapters, professional baseball teams, and local radio stations. In various U.S. cities, radio stations dedicated up to 12 hours of radio time to inform listeners about ALS. During these activities, people with ALS and their families shared their stories on air about life with the disease; radio personalities interviewed celebrities such as onetime Los Angeles Dodger/San Diego Padre Steve Garvey; and disc jockeys took listeners’ calls and provided information about awareness happenings at area baseball parks.

As it does each baseball season, the Phillies Phestival offered residents of the “City of Brotherly Love” with the chance to mingle with members of their favorite team. This annual event includes an autograph party where Philadelphia Phillies players meet and greet their fans as well as live and silent auctions. Started in 1984, the Phestival has raised close to $12.7 million for the Greater Philadelphia Chapter, and its 2011 activities brought in an impressive $893,033 to fund research and patient services. More than 6,800 fans showed up at this event on June 13 held at Citizens Bank Park.

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At Yankee Stadium, the Dessi Family with Greater New York Chapter President and CEO Dorine Gordon stand on the ball field with a donation to the chapter from the Bronx Bombers and a team-signed home plate.

When she couldn’t talk...I could still see the love in her eyes,” recalls John Runnion, grandson of Jeanne Frances Henckel Critton. John is one of seven family members who recently recorded a spoken remembrance as part of the family's Promise Fund tribute to Jeanne, affectionately established by her husband, Bob Critton. The family's loving and enduring celebration of Jeanne's life supports the vital work of The ALS Association's Keith Worthington Chapter, serving Kansas, Nebraska and Western Missouri.

As the extended Critton family discovered, the Promise Fund can be a meaningful way to share treasured memories with generations to come. Family stories, photos, video, and recorded oral tributes are permanently captured and artfully presented on a family's customized web page. The spoken remembrance or audio recording is a particularly meaningful way to remember the kindness, courage and humanity of important people in our lives.

Brooke Runnion, granddaughter of Jeanne, and a board member of the Keith Worthington Chapter shared in her spoken remembrance: “One passion I wish I had inherited from my grandmother was her enthusiasm for gardening. As soon...
as the weather got warm she just loved to put on this bright yellow cotton two-piece and go out into the garden and start snipping. In some cases she actually snipped and pulled to the extreme! She was relentless in her pursuit of having the perfect yard.”

Many Promise Fund families have shared that their web page in honor of someone they love is a very real “place” where they can go to visit and remember. Promise Funds can be established to support the full mission of The ALS Association or an area of special interest to the family. If you would like to experience Jeanne’s story in its entirety and those of other families, we encourage you to visit www.ALSpromise.org.

Make Your Promise Today

The Promise Fund is one more way we honor those on the front lines of this disease. We invite you to establish an ALS Promise Fund and share your love for someone special. Whether you’ve lost a cherished family member or friend, want to show appreciation for an extraordinary caregiver or highlight the efforts of someone who has made a difference during your family’s struggle with ALS, the Promise Fund is a unique and lasting tribute. It reflects not only a celebration of life and those we hold dear, but also...a promise to create a tomorrow without ALS.

For more information about how you can establish an ALS Promise Fund, please contact your local chapter of The ALS Association or Karen Starleaf at kstarleaf@alsa-national.org or (818) 587-2211.

Critton Family’s Promise

Continued from page 4

Dynamic ALS Research Webinars

Since March 2011, The ALS Association has been sharing groundbreaking research with the ALS community in webinars hosted by ALS Association Chief Scientist Lucie Bruijn, Ph.D. In this series of monthly webcasts, information is provided on riveting ALS Association-funded studies and ongoing collaborative efforts among researchers. These are presented by world-renowned scientists and innovators in the field who lend their expertise to expound on advancements in ALS research.

Bryan Traynor, M.D., of the National Institute of Aging, kicked off the first research webinar on the subject of Whole Exome Sequencing and detailed this revolutionary technology, which has already led to one gene discovery, called VCP (valosin-containing protein). Subsequent presentations were devoted to the role of TDP-43 in ALS, Electrical Impedance Myography as a Biomarker, and the ALSoD Database.

Ashkan Javaherian, Ph.D., Senior Scientist at iPierian, provided an exciting update on “induced pluripotent stem cells” (IPS). IPS is a technique that allows scientists to convert skin cells into stem cells and have the potential to become a powerful tool for understanding the ALS disease process as well as for rapidly discovering drugs to treat the disease. The biotechnology firm uses skin cells from ALS patients as the starting point for growing millions of motor neurons. These neurons can then eventually be tested against thousands of drugs with the goal of finding a compound that reverses some aspect of the disease, such as cell death, signs of stress, or expression of some disease-related protein.

After the webinar presentation, attendees are invited to ask questions using the chat feature, for a response from Dr. Bruijn or the presenting field expert.

“We are excited to be able to raise the level of awareness about specific areas of high potential and in such a way that it can be understood by all those attending the call,” said Dr. Bruijn. “In addition, these webinars allow the ALS community instant access to these researchers and ignite discussions about topics pertinent to the progress being made in ALS research.”

To participate in future webinars or access links and summaries of previous presentations, visit http://www.alsa.org/research/research-webinars.html.

Dean Rasmussen’s Indelible Legacy

By Stephanie Dufner

Dean Rasmussen became involved with The ALS Association in 1989 shortly after his father, Carl, died from ALS at age 69. “I believe this is my life mission to find a cure for Lou Gehrig’s Disease,” said Rasmussen, who is the 2011 recipient of The Association’s Packman Award for expanding awareness of ALS and The Association and advancing the organization’s goals.

Rasmussen first embarked on this personal task through sponsoring The Association’s research program; then he began working to build contacts with members of the U.S. Senate and House of Representatives and employees at the Department of Defense and National Institutes of Health. Such connections have enabled The Association to encourage Congress to waive the 24-month Medicare waiting period and to pass the ALS Registry Act.

“I realized that through advocacy we could actually multiply the support for our research program by encouraging the support not only of individuals, but also by gaining the backing of those in decision-making roles within our government,” Rasmussen said.

Make Your Promise Today

The Promise Fund is one more way we honor those on the front lines of this disease. We invite you to establish an ALS Promise Fund and share your love for someone special. Whether you’ve lost a cherished family member or friend, want to show appreciation for an extraordinary caregiver or highlight the efforts of someone who has made a difference during your family’s struggle with ALS, the Promise Fund is a unique and lasting tribute. It reflects not only a celebration of life and those we hold dear, but also...a promise to create a tomorrow without ALS.

For more information about how you can establish an ALS Promise Fund, please contact your local chapter of The ALS Association or Karen Starleaf at kstarleaf@alsa-national.org or (818) 587-2211.
Rasmussen’s Indelible Legacy
Continued from page 5

The Association’s Board members and staff laude him for his determination and foresight. In presenting the Packman Award to Rasmussen in May 2011, National Board of Trustees Chair Jay Daugherty said, “For him, ALS is personal, and all of his efforts bring more people into our fight and truly advance the goals of The Association to find a treatment and cure for ALS.”

Rasmussen’s pursuit to eradicate Lou Gehrig’s Disease pushed him to enact legislation that has benefitted everyone fighting ALS.

Dean and Kathleen Rasmussen

Longtime Trustees Expertise
Continued from page 2

Southern California in the mid-1980s with others from the ALS community in that area.

Winston’s devoted service at the chapter demonstrated her leadership abilities, and she became a National Board Trustee in 1987. She served as the board’s secretary from 2002–2011, and served on several committees, but patient care was her special interest.

As a patient care advocate, Winston played a key role in the development and growth of The Association’s ALS Certified Centers and clinical management research programs during her time as chair of the Patient Services Committee from 2000-2011.

“Laural’s efforts were instrumental in securing funding necessary to support the most comprehensive clinical care possible across the country,” said Mary Lyon, R.N., MN, former vice president of patient services who worked with Winston from 1998–2005. “Her leadership and support resulted in the development of the only national clinical conference in the country for allied health care professionals including an additional track for the nurses at The Association’s certified centers.”

In addition to serving as chief benefactor of ALS advocacy, Rasmussen was a member of the National Board of Trustees from 1993–2006 and volunteered on the Finance, Research, Community Services and Advocacy Committees. He also served on the board of The Association’s Greater Los Angeles Chapter (currently The Golden West Chapter) where he and his wife Kathleen have raised funds for annual Walk to Defeat ALS® events.

“His impact on The ALS Association’s advocacy and research efforts shows his steadfast resolve to increase ALS awareness and promote multiple avenues that will help us relegate this dreadful disease to history,” said Golden West Chapter President and CEO Fred Fisher.

“Dean has left an indelible imprint on our organization as a whole, and every day, he inspires us to continue to fight ALS,” Fisher said.

Most Common Cause
Continued from page 1

Following Up On This Major Milestone

The ALS Association is eager to fund new research projects that result from this finding. We also anticipate the following specific developments to occur:

• Geneticists across the globe are actively searching for the presence of this gene abnormality in groups of people with ALS and FTD. The results from their effort will further substantiate the percentage of ALS caused by this gene mutation.

• To spark new avenues of research that build on this significant finding, plans are underway for a scientific workshop to be held in the next few months.

• A diagnostic test is being developed for ALS and FTD.

• Scientists are already working to build animal and other model systems to further understand how this gene functions and to identify targets for drug development.

“The ALS Association salutes Drs. Traynor and Rademakers, their teams and their collaborators,” said ALS Association President and CEO Jane H. Gilbert. “We are proud to have supported their research and congratulate them on the announcement of this truly significant discovery. Through your generous support, we will continue to ensure ALS research that will bring us to effective treatments and someday, a cure.”

Visionary Leaders

Griffith, Ohrenstein, and Winston shared a commitment to educating others about ALS; their service and compassion for those living with the disease allowed The ALS Association to successfully pursue its mission. Each of them understood the challenges those with ALS face, and these three leaders collectively and individually contributed their time and talents toward creating and overseeing programs and services that benefit individuals and their families fighting Lou Gehrig’s Disease.

For their efforts, The ALS Association extends profound gratitude toward these retired trustees—as well as to other former and current members of the National Board of Trustees—who have supported and advanced the organization’s vision of a world without ALS.
It was a match made in heaven—or more accurately, a high school gymnasium.

The year was 1967, and Gene Schmidt was working as the boys’ P.E. teacher at a high school in a Chicago suburb. Just 22, he was funny, outgoing and athletic and had recently graduated from Western Michigan University, which he had attended on a baseball scholarship. As it so happened, another recent college grad—a tall, pretty woman named Sandra—got a job as the girls’ P.E. teacher at the same school. It was only fitting that they fell in love.

“I guess you could say it was a high school romance,” Sandra said, laughing. “The kids thought it was wonderful.”

Two years later, they were married—beginning a life together that would span three decades. The Schmidts had a son, Zach, and then a daughter, Casey. Gene became a school superintendent and later launched a career in finance in New York. Sandra, meanwhile, became an elementary school teacher, a reading specialist and later, a special education teacher for elementary and middle schools. “We weren’t perfect people or anything. We had our problems like everyone else,” she insists. “But we were happy.”

Then, ALS intervened. The first symptoms started in 1989. Gene had started to complain about a numb and tingly feeling in his hands. He thought it was carpal tunnel syndrome from too much time on the computer. An orthopedic doctor sent him to a neurologist, and several months later, he was diagnosed with ALS. He was 44. Zach was 13, and Casey was only 10.

“We were actually fortunate, because his disease progressed slowly,” Sandra said. “He was mobile for a long time. Even at the end, he could still walk with help.”

In 1998, nine years after his first symptoms, Gene passed away at the age of 52. Since his death, Sandra has been a committed supporter of ALS research and The ALS Association. Now retired with three granddaughters, she recently completed her third charitable gift annuity for The ALS Association.

“I guess I give for selfish reasons, because of Gene and everything he went through,” explains Sandra, who lives on Long Island, N.Y. “I very much would like to see the day when science knows how to prevent ALS or stop it from progressing.”

The daughter of an Indiana firefighter who worked a second job to send his five children to college, she said that growing up, her family had little money left over for charity.

It was Gene who taught her the importance of giving back. For years, he volunteered to run fundraising events for a local cystic fibrosis organization. He also volunteered for the YMCA and local schools.

“He always felt strongly that we needed to give back to society. I learned that from him,” she said. “I can’t think of a better way to honor him than to give back to fight ALS.”

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* These rates are valid as of July 1, 2011 and are subject to change. Please contact us for rates at other ages. Rates shown are for one beneficiary. Ask us about rates for two beneficiaries.

We recommend you seek the advice of an estate and/or tax professional in connection with any gift.
Sanofi-Aventis and The ALS Association Team to Offer ALS Information in Spanish

By Amber Walters

The ALS Association empowers people diagnosed with ALS and their families to lead fuller lives by providing compassionate care, support and educational information about Lou Gehrig’s Disease. In partnership with Sanofi-Aventis, a diversified global healthcare leader, The ALS Association is excited to provide select pieces of ALS educational materials translated into the Spanish language.

Two of our brochures, “We are with You Every Step of the Journey” and “Your Resource Guide to Living a Fuller Life with ALS” as well as the DVD, “You are not Alone” are now available in both Spanish and English. The first brochure is a guide to The ALS Association Certified Centers℠ and the supportive services they offer. The second brochure and its companion DVD are designed for people who have been recently diagnosed with ALS and their loved ones. These items can either be downloaded and viewed instantaneously or ordered via our library order form online at www.alsa.org under the Resources section for people with ALS and caregivers. These materials are free of charge to people with ALS and their family members.

In addition, visitors to our website can access either the Spanish or English versions of the “About ALS” section. This segment contains important information about what ALS is and who it affects, general facts you should know, details about common symptoms and the diagnostic process, forms of ALS, and a question and answer component pertaining to genetic testing for ALS.

The Spanish translation of these valuable materials were made possible by a generous grant from Sanofi-Aventis, the pharmaceutical manufacturer of Rilutek®, which is the one FDA-approved drug shown to have a moderate affect on delaying disease progression.