The ALS community mourns the recent loss of Richard Olney, M.D. A world-renowned ALS researcher and physician, he studied and treated people with the disease for nearly 30 years. He died on January 27, 2012, after an eight-year battle with Lou Gehrig’s Disease.

Dr. Olney worked closely with The ALS Association and its Golden West Chapter and founded the ALS Research and Treatment Center at University of California, San Francisco in 1993. The Center, which The Association declared an ALS Certified Center of Excellence in 2001, offers people with ALS supportive, multidisciplinary care in an atmosphere that emphasizes hope and quality of life.

“Dr. Olney inspired a whole generation of students who studied under him,” said his onetime protégé and colleague, Catherine Lomen-Hoerth, M.D., Ph.D., the current director at the center, a position Dr. Olney held from 1999 to 2004. In 2004, Dr. Olney appeared in The Association’s “Keep Hope Alive” television public service announcement. The PSA aired on network television and currently appears on The Association’s YouTube Channel at http://ow.ly/9OrjD. Several news outlets, including The New York Times, “CBS Sunday Morning” and People magazine, profiled Dr. Olney and discussed his ALS diagnosis in recent years.

“Dr. Olney has been a model of courage to those of us who work every day to understand the disease…” – Lucie Bruijn, Ph.D.

“Dr. Olney has been a model of courage to those of us who work every day to understand the disease…” – Lucie Bruijn, Ph.D.

The gene C9ORF72 has emerged as the most common cause of familial ALS, likely accounting for more than one third of all people with an inherited form of the disease and a smaller but significant proportion of those with the sporadic (non-familial) form. The gene is also responsible for some forms of frontotemporal dementia, another neurodegenerative disease. The function of C9ORF72 is unknown, but it is now a subject of intense research. Another gene, Ubiquilin-2, responsible for a relatively smaller number of cases, is involved in breakdown of damaged proteins. This suggests that problems with that process are central to ALS due to other causes as well.

“These new genes will be critically important as we move to understand the
New Statewide Chapter to Serve ALS Community

By Robert Ward

Texas! The Lone Star State covers 260,000 square miles, has a population of almost 21 million people, and includes hundreds of cities and towns. It is beautiful and richly endowed with natural resources. Its diverse people are motivated by an indomitable spirit.

Tragically, 1,000 of them have ALS.

Effective February 1, 2012, those with Lou Gehrig’s Disease in the state have access to the Texas Chapter of The ALS Association. The new chapter is the product of the consolidation of the three regional chapters that previously served Texans fighting ALS—the North Texas Chapter based in Dallas-Fort Worth, the South Texas Chapter in San Antonio, and the Greater Houston Chapter.

The new chapter will be led by David Chayer, Executive Director. Chayer is an experienced chief executive and will serve with Board President Robert Kraemer, who was previously a board member and board chair of the South Texas Chapter.

A statewide chapter will provide more accessible, consistent and effective services to ALS families throughout Texas. It will also create opportunities to attract support from donors and volunteers across the state.

The state program director will head the chapter’s Care Services Department. This individual will lead staff in each of three regions, who will provide access to clinic services, oversee equipment loans, support groups and respite care, and manage community outreach. Offices will remain in Houston, San Antonio, Austin, and the Dallas-Fort Worth area. In addition, those with the disease will continue to have access to Baylor College of Medicine in Houston and The University of Texas Health Science Center at San Antonio.

“We want to serve every person battling ALS in Texas and every family supporting them. The new Texas Chapter will help us do that,” said Kraemer.

Increasing financial resources is also a top priority. Texas is home to 51 of the nation’s top 500 companies. “We have a tremendous opportunity to increase business community support. Being a statewide organization will help us do so,” Chayer said. “We will also grow support from our many thousands of loyal donors. Our Walks to Defeat ALS® will continue to grow.”

Chief Chapter Relations Officer Ken Nicholls at the national office of The ALS Association and Chapter Relations Director Donna Gracon, provided counsel and operational expertise to the merger team. “The new Texas Chapter is built upon an outstanding collaborative effort. We look forward to supporting the chapter as it fulfills its statewide mission,” Nicholls said.

ALS Association President and CEO Jane Gilbert is pleased with the establishment of the Texas Chapter. She said, “The new chapter will provide high quality service for every person in Texas who needs us. It will speak with a strong voice throughout the state on ALS patient services, research and public policy. This is a devastating disease. The Texas Chapter will help us fight and defeat it. I congratulate David Chayer, Bob Kraemer and their colleagues and extend thanks to everyone who contributed to the merger’s success.”

In more ways than one, The ALS Association has come to a new chapter in its history of service in the Lone Star State.
Bruce Edwards was determined to fight ALS for as long as he lived—and even after he was gone. Diagnosed in 2009, Edwards approached ALS in the same way he had approached everything in his life: with a winning spirit and a drive to achieve. His Walk to Defeat ALS® team, Bruce’s Battalion, raised nearly $60,000 in just two years. That made it the highest revenue-producing Walk team in the history of The ALS Association’s Keith Worthington Chapter, which serves Kansas, Nebraska and western Missouri.

However, late last year, as Edwards realized that his battle with ALS was coming to a close, he sought a lasting way to continue the fight. His answer: The Bruce Edwards ALS Promise Fund http://www.alsa.org/bruceedwards.

“The fight and funding to end ALS must continue long after I am gone,” he wrote on his Promise Fund site. “While I may not be here…your commitment will give me comfort knowing others will be helped.”

Edwards passed away Jan. 26, 2012; he was 54. Nonetheless, his wish to fight ALS well into the future is coming true. Incredibly, his Promise Fund already has raised more than $20,000.

An ALS Promise Fund gives people with ALS and their families an opportunity to share their stories through a special Web page complete with photos, videos, and even spoken tributes or remembrances. Visitors have a chance to honor and remember—and to donate to the fund to support critical ALS research and patient care services.

The minimum pledge to establish a Promise Fund is $25,000. The gift may be made over a period of up to five years. Most Promise Funds have been established by family members after a loved one’s death. True to his groundbreaking ways, Edwards was the first person with ALS to establish a Promise Fund. He and Janie made a $100,000 commitment.

“Bruce had an eternal optimism that was contagious and inspired all of us to live life to the fullest,” said Beckie Cooper, executive director of The Keith Worthington Chapter. “He left a lasting impression on everyone he met.”

One of those people was golf legend Tom Watson. Watson had become involved with The Keith Worthington Chapter when his caddy, coincidentally also named Bruce Edwards, battled ALS a decade ago. To see a Watson’s video on Bruce Edward’s Promise Fund homepage, visit http://www.alsa.org/bruceedwards.

When Watson learned that there was another Bruce Edwards in his hometown who had ALS—and who lived on Tom Watson Parkway—he had to meet him. Later, he presented Edwards with the Tom Watson Award for Courage.

“Courage is not something you can teach or give someone,” Watson said in a video tribute on Edwards’ Promise Fund page. “It’s something that resides within, rises to the occasion when you need it, and definitely captures what is unique about Bruce.”

For more information on establishing 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.
Bringing the Fight to Local Communities

By Laurel Rosenthal

In March 2011, The ALS Association created an online platform to help our constituents in the ALS community to plan and create third party events that raise critical funds for our mission. Throughout the year and across the country, 180 various events were created that raised more than $420,000. The unprecedented success of the One Dollar Difference program signifies the passion of our supporters, who take a firm stance against Lou Gehrig’s Disease. The money raised by these third party events provides funding for the services to families living with ALS and funding for our groundbreaking research programs.

Throughout the year, ALS advocates organized events, whether big or small, to rally friends, family, and local communities together to bring the fight against ALS to their back yard. Whether it was a bake sale, a climb up Mount Kilimanjaro, a bicycle endurance event, or a backyard barbeque, our advocates partnered with thousands of people to further grow our fight against ALS. It doesn’t matter if someone is running in a marathon or wants to organize a dinner party; anyone can create a One Dollar Difference event. The sky’s the limit!

Through the One Dollar Difference, constituents are empowered with online tools that allow participants to create event web pages, send emails to family and friends, and collect donations towards their event. What makes One Dollar Difference so successful is that anyone can create an event anywhere at any time to benefit The ALS Association. Please contact your local chapter or go to www.onedollardifference.org to get started today!

After months of experiencing symptoms such as muscle stiffness or twitching and visits to multiple doctors, receiving a diagnosis of ALS can bring on a host of reactions. Among the emotional responses are denial, devastation and an eagerness to try almost anything promoted as an effective treatment or potential cure. You know ALS will impact every facet of your life. You ask yourself, “Where do I start my quest for information, education and assistance?” The answer: your local ALS Association Chapter.

The ALS Association’s chapters and their professional care services coordinators and directors provide education, compassionate care and support for those living with ALS and their families. In 2011, chapters directly served nearly 12,000 persons living with the disease across the country. Information about ALS is available via telephone or computer, and at times may even be shared with you and your family in the privacy of your own home. Education related to the diagnosis, care and treatment of ALS is available to those diagnosed with the disease and their families and friends through support group meetings that chapter professionals facilitate. Many chapters have specific programs to address the concerns and needs of those providing caregiver services during the journey with ALS. Care Services professionals can provide referrals to resources for medical care and services, as well as provide assistance in navigating the complex transition between private and public health care insurance and benefits.

Upon receiving an ALS diagnosis, Kim and Donald Purdy reached out to the Northern New England Chapter. “We needed information immediately. We wanted someone to let us know what we were in for and to listen to our concerns,” said Kim Purdy. “It’s crucifying to hear this diagnosis. The ALS Association Chapter Care Services director helped us learn coping skills, and the chapter support cushioned the blow and provided a bridge to additional help in the community.” As her husband’s disease has progressed, Purdy said, “The chapter continues to provide invaluable services. They’re helping us row the boat.”

In addition to providing such direct assistance, Care Services experts provide clinic liaison services at ALS Association Multidisciplinary Certified Centers of Excellence. Receiving services at these centers has been shown to increase the life expectancy for those diagnosed with ALS. Collaboration with organizations such as the Congressionally-chartered Paralyzed Veterans of America (PVA) has also improved the speed with which many veterans diagnosed with ALS are able to access military service-connected benefits. Chapters share the latest leading-edge care and therapy with local health care providers by presenting professional educational programs and symposia.

“Our Care Services professionals provide many resources to families dealing with ALS,” said Association Chief Care Services Officer Kimberly Maginnis. “We understand people dealing with this disease can often feel overwhelmed with questions related to in-home care, community support services and health insurance.”

Care Services programs, including lending equipment, augmentative communication, respite services to caregivers and transportation, are available through many chapters. In addition to delivering “practical” services, chapters also recognize that ALS is a comprehensive diagnosis that affects an individual and their entire circle of family and friends. The multiple issues impacting one’s physical condition, emotional status, financial situation and social and family relationships can seem insurmountable to those diagnosed with Lou Gehrig’s Disease. However, compassionate assistance, care and support in addressing these challenges can be obtained by making a single call to your local ALS Association chapter. You can access The ALS Association’s National Care Services toll-free resource line at 800-782-4747 or find your local chapter by visiting http://www.alsa.org/community.
Often times, when a department undergoes a name change, it reflects a modification in the goods or services that unit offers. The ALS Association’s Care Services Department has held the moniker ‘Patient Services’ since the organization’s inception in 1985. In 2011, however, The Association’s leadership decided to change the department’s name to Care Services to more accurately reflect how the department assists its constituents.

“Patient Services sounded misleading,” said Chief Care Services Officer Kimberly Maginnis, who joined The ALS Association in January 2012. “That title suggested that we provided direct medical or health care, which has never been the case. The term ‘Care Services’ more accurately reflects how we serve people with ALS, their families and caregivers as well as our chapters, multidisciplinary centers, community health practitioners, and the general public.”

**Different Name, Same Functions**

Those who work in the national Care Services Department provide information to people seeking answers to questions about a diagnosis of Lou Gehrig’s Disease. Department employees respond to emails and phone calls and often refer those who contact them to an ALS Association chapter in their geographic area. Also, the department hosts free, monthly Webinars in conjunction with clinical experts from the ALS community and works closely with medical liaisons to certify ALS Association Centers of ExcellenceSM and clinics.

“In addition to acting as a referral resource and frequently interacting with people skilled in ALS care, we work closely with our chapters to ensure they deliver knowledge and services in an effective manner,” said Care Services Director Cynthia Knoche, RRT, BBA. This collaboration with chapters can include facilitating support groups, operating equipment loan programs, and directing people battling the disease to neurologists who specialize in ALS care.

**Goals will Facilitate Better Care for those on the Frontlines of the Disease**

Since joining The Association, Maginnis has come to understand the important role the department plays in the organization’s mission of “providing compassionate care and support to people with ALS and their families.” Maginnis has 30 years healthcare experience, including leadership roles at Inova Health System, Harvard Community Health Plan, and the Veterans Administration. Aside from overseeing the development of Care Services’ policies and programs, she interacts with chapter staff and volunteers to plan, implement and evaluate local Care Services programs.

Maginnis believes her unique skill set, which combines a keen business acumen and clear understanding of clinical practices, will enable her to develop programs and processes that support The Association’s goal to offer every person with ALS high quality and consistent patient care.

“I envision those working in Care Services—on both the chapter and national levels—to further develop their competencies for working in both clinical and non-clinical settings,” said Maginnis. “Whether ALS Association employees directly interact with medical professionals or caregivers, continuing their education in ALS care practices enables our staff to continue to perform in a competent, compassionate manner. It also gives them the knowledge to empower those who matter the most, people with ALS and their families.”

**Care Services—What’s in the Name?**

**New Care Services Leader Aims to Bolster Programs that Support People with ALS**

By Stephanie Dufner

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TREAT ALS: New Grants

Continued from page 1

disease process more completely,” according to ALS Association Chief Scientist Lucie Bruijn, Ph.D.

An important new project being funded by the TREAT ALS program is the development of cell and animal models incorporating C9ORF72. The project led by ALS researchers Robert Brown, M.D., and Chris Shaw, M.D., will allow scientists to explore exactly how the mutation leads to the death of motor neurons. It is known that the mutation causes accumulation of Ribonucleic acid (RNA), which may be directly toxic or may disrupt other cellular processes.

The importance of RNA in ALS is highlighted by the fact that two other ALS genes, TDP-43 and FUS, are involved in RNA processing. “The discovery of these genes, in 2008 and 2009, and now the discovery of C9ORF72, has opened a critical window into understanding the ALS disease process,” said Dr. Bruijn.

“As we move ahead, we will be focused on learning how they may interact to cause ALS and to use that knowledge to develop new treatments.”

Other studies funded by the TREAT ALS program include:

- A genome-wide search for new genes is being undertaken in Ashkenazi Jewish people with ALS. Because Ashkenazi Jews are a more homogenous group than the general population, the odds of finding ALS-causing genes are increased in this group.

- A pair of studies will work to increase our understanding of how cells break down proteins. In ALS, proteins may accumulate in motor neurons, causing damage. A better understanding of the normal mechanisms for protein clearance may identify targets for therapy.

The program is also funding two therapeutic trials:

- Nuedexta is a drug approved for reducing emotional liability in ALS patients. Researchers will test whether it may also improve speech and swallowing in the same patients.

- Introduction of human spinal cord derived stem cells (HSSCs) into the spinal cord of ALS patients has been shown to be safe. In the next phase of this trial (Neuralstem), investigators will increase the number of HSSCs delivered to determine safety of the maximum tolerated dose.

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This year marked the 70th birthday of Stephen Hawking, best-selling author of *A Brief History of Time*, a layperson’s compendium to the cosmos. When he was diagnosed with ALS at the age of 21, doctors told Hawking he had only two years to live. The British physicist, however, has defied this prediction and has lived a prolific life as a father, Cambridge professor, and one of the most respected scientists of our time.

An estimated 10% of people battling Lou Gehrig’s Disease can live for more than 10 years with the disease. Like Hawking, septuagenarian John Riggs is in the small percentage of people who have fought ALS for more than two decades. Initially diagnosed with the disease in November 1981, physicians who gave Riggs “second opinions” expected him to survive for only a few years. “When my primary care doctor said he thought I might have ALS, I had no idea what he was talking about,” said Riggs. “When he said ‘Lou Gehrig’s Disease,’ I knew I was in deep trouble. The only thing I knew about ALS was that it is terminal.”

Both Hawking and Riggs represent atypical persons with Lou Gehrig’s Disease. “It is unusual for ALS patients to survive for decades, but it is not unheard of,” said Rup Tandan, M.D., FRCP, Professor and Vice Chair of Neurology at the University of Vermont, College of Medicine. Tandan explains that most people with the disease die of respiratory failure. However, factors such as utilizing mechanical ventilation, which aids in breathing and using the FDA-approved drug riluzole can increase the survival rates of those battling the disease.

Neither Hawking nor Riggs relies on mechanical ventilation, yet both utilize motorized wheelchairs for mobility along with computers to communicate with family, friends and colleagues. The latter uses his Apple computer for daily interactions with his three sons, Mike, Joe, and Brian, and the assisted living staff at the residence where he lives in San Jose, California. Riggs, who trained and worked as a chemist, reveals he lost the ability to speak in the early 1990s.

Scientists do not know what causes ALS; they question whether genetics, physical activity, or environmental exposures can trigger the disease.

Tandan admits further study of the biology of the disease as well as the genes that might control its “biological behavior” may provide clues to why some with ALS have shorter survival periods than others. “In some rare cases, ALS patients can have a very slow progression of their disease,” Tandan said. Again, ALS researchers cannot determine what could decelerate the disease in some people.

Riggs said that physicians never have told him that he has a slowly progressing form of ALS. However, he echoes Hawking’s sentiments in attributing his long life to strong personal and professional ties. “I credit my survival to the love and support I have received from my sons, my sister and two brothers, high school and university classmates, many friends and caregivers and most of all, the grace of the Holy Spirit,” he said. “I thank God every day for my three sons and three adorable granddaughters.”

The Defiant Ones

Scientists Question How a Small Percentage of People with ALS have Survived for Decades

By Stephanie Dufner

“I thank God every day for my three sons and three adorable granddaughters.”

—John Riggs
The Gift of Remembrance

By Phyllis Freedman

Nearly ten years after the death of her high school sweetheart and beloved husband, Tom, from ALS, Jayne Cawthern still has a catch in her voice when she speaks about the man who left this world far too early yet had a profound impact on so many during his life.

“My greatest fear is that he won’t be remembered,” she said. “We keep a ‘Dad’ book with Tom’s favorite expressions in it as a reminder. Our youngest child was only nine when her father died, so it’s important to keep his memory alive.”

Keeping Tom’s memory alive is a passion Cawthern shares with each of her six children and with the wide circle of friends and colleagues who knew and loved him. Tom went to medical school and worked as a pathologist. After his diagnosis, each of his partners pitched in so he could continue to work for as long as possible. Another friend visited regularly, encouraging Tom to go out with them. “Both friends and colleagues were gifts to our family,” Cawthern said.

“The ALS Association was also a gift. I truly believe God was looking out for us the day He brought us to them,” said Cawthern. “They were always five steps ahead of us. While we were still coping with the diagnosis, they pushed us to adapt the house and for Tom to be measured for a motorized wheelchair. We couldn’t have survived without them,” she said.

Today, Cawthern’s entire extended family and network of friends and colleagues are giving back that gift. “All the kids are putting fundraising messages on Facebook and doing Walks,” said Cawthern. “And the people who knew Tom are contributing, too. Every year on Tom’s birthday, I get a notice that a gift has been given in his honor.”

Cawthern has made a provision in her will for The ALS Association along with each of her six children. With determination in her voice, she said, “My will is divided seven ways. If I have seven dollars left, The Association will get one. It’s a priority. Once it happens to you, you either try to never think about it again, or you find satisfaction in doing what you can so other people don’t have to suffer.”

Tom Cawthern used to come home from work, have dinner with his family, and then reexamine the pathology slides he’d reviewed that day. He knew that someone’s life might depend on the outcome. Jayne Cawthern knows that someone’s life—many lives—may depend on her bequest. “I’m determined to do what I can to help find a cure. I would donate every penny I have if I could,” she said. “So I’m telling my story now in the hope that it will inspire others, and I will feel comforted knowing that my bequest will help even after I’m gone.”

If you have any questions about leaving a bequest or would like to discuss which planned giving option is best suited to your circumstances, please contact David Moses, Director of Gift Planning, toll-free at (888) 949-2577, ext. 212 or dmoses@alsa-national.org. All inquiries are strictly confidential.

By Patrick Wildman

This May, the ALS community once again will join together as we continue the fight against ALS at the 2012 National ALS Advocacy Day and Public Policy Conference in Washington, D.C. Thanks to the efforts of advocates across the country who have told the ALS story to their elected officials, we have realized many significant successes, from creating the National ALS Registry and expanding benefits for veterans with ALS to waiving the 24-month Medicare Waiting Period for people with ALS and generating over $650 million in funding for ALS research.

Thanks to the advocacy of people with ALS and their families, our government is now the single largest source of ALS research funding in the world. It also has created an environment that has helped make many advances in ALS research possible—advances that may result in the first new treatments for ALS since 1995!

However, the nation’s economic climate, the federal budget crisis, and Presidential election year politics pose significant threats to this progress. That’s why The ALS Association invites you to join us in the nation’s capital May 13-15 for this year’s Conference in Washington, D.C. Thanks to the advocacy of people with ALS and their families, our government is now the single largest source of ALS research funding in the world. It also has created an environment that has helped make many advances in ALS research possible—advances that may result in the first new treatments for ALS since 1995!

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Registration for the 2012 Conference is now open. Go to www.alsa.org/advocacy/advocacy-day to see the exciting conference agenda, which this year includes four plenary sessions devoted to ALS research, including presentations by Biogen Idec, Cytokinet-ics, ISIS and Neuralstem. Register to attend the conference and help us continue to create the roadmap that will lead to a treatment and cure for ALS.
Minor League Baseball Helping to Strikeout ALS

By Mark Murtagh

Spring means Opening Day for baseball teams across the country, but this season the boys of summer will be looking to strikeout more than just their opponents. That’s because The ALS Association is partnering with Minor League Baseball to launch a comprehensive awareness campaign to strikeout ALS at ballparks across the country. The campaign includes: advertisements about ALS placed in game day programs; on-field ceremonies to pay tribute to people with ALS; public service announcements to be played on video scoreboards and read over park PA systems; and people with ALS being featured as part of game day radio and television broadcasts, among other promotional activities.

In addition to raising awareness of ALS, the campaign will bring new attention to our cause by highlighting the fact that our military heroes are twice as likely to develop ALS as the general public. In fact, fans can make and send e-cards thanking our military heroes for their service. The campaign also will help to promote enrollment in the National ALS Registry, which is a key component in the fight against the disease and can help us learn what causes ALS and how it can be treated or even prevented.

Events will be held by participating teams throughout the 2012 Minor League Baseball season.

Research Webinars

Knowledge is power, and those from the ALS community who attend The ALS Association’s monthly Research Webinars can gain a better understanding of the scientific underpinnings of Lou Gehrig’s Disease.

Since we started broadcasting these Webinars in spring 2011, approximately 700 people have participated in these events. Chief Scientist Lucie Bruijn, Ph.D. hosts the Webinars, which explore myriad topics pertinent to the disease. Previous subjects include “The Role of TDP-43 in ALS,” “Understanding the Relationships Between Gene Variations and Patterns of ALS: The ALSoD Database,” and “TREAT ALS/NEALS Clinical Network.”

To see past presentations or learn how to participate in future webinars, visit http://www.alsa.org/research/research-webinars.html.