The mass spectrometer is an analytical instrument with interpretive software that allows the ‘fingerprints’ of drugs or larger proteins to be examined and identified. Advances in this technology are being exploited in all areas of therapeutic development, from new drug design in biotechnology to monitoring clinical trials by large pharma.

Thanks to your continued leadership, ALS TDF recently added a new Mass Spectrometry Core to our lab, and hired veteran scientist Dr. Nels Mahle to run it.

Typically, when a decision is made to place a potential therapeutic through a study with the ALS mouse, ALS TDF performs an initial study to assess the ability of the drug to reach the spine in the desired levels. Confidence that this analysis is properly
Your laboratory at ALS TDF has nearly three times the capabilities it did this time last year. The world-class therapeutic development program we built together comprehensively evaluates nearly all promising therapies seeking ones that will truly impacts ALS.

ALS TDF has completed more than twice the number of studies than have been published by all other ALS research programs combined. You should be proud of the work we’ve done together — but finding answers demands we do more.

Today, we’re launching a new discovery research program that will let us dissect ALS piece by piece, gene by gene and protein by protein. Combined with our therapeutic development program, we will evaluate comprehensively each potential target until we find one or several that truly impacts ALS.

ALS TDF’s new Gene Expression Core will let our scientists quantify even the smallest changes in gene expression — which, in time, could help us find both new targets for treatment and biomarkers of disease progression.

We're also improving our therapeutics discovery process. The construction of our Biosafety Level 2 laboratory last year paved the way for in-house cell and gene therapy experiments, vital in developing new gene-therapy based target validation and treatment approaches. Our new internal full-scale Mass Spectrometry Core — which we use to analyze drug penetration in blood and tissue — improves the quality and value of all our drug studies.

These new resources, coupled with our ongoing therapeutic development program, make ALS TDF the most advanced ALS research program in the world.

Thanks to all who have supported our mission and give me hope for a future where we do not fear ALS. It's the combined leadership of our research team and everyone involved that makes ALS TDF possible.

Sincerely,

James Allen Heywood
d'Arbeloff Founding Director
and accurately performed allows us to make the strongest conclusions on drug efficacy from the mouse study.

The identification of the distinct drug and the level of the drug in the target spine tissue is vital for testing potential therapeutics in an ALS mouse study.

“Without testing the mouse tissue, it is not possible to determine if a negative result in mice reflects a lack of drug efficacy or lack of targeting to the spinal cord tissue,” says Nels. “This analysis can be performed using mass spectrometry.”

Prior, mass spectrometry analysis was supplied to ALS TDF on a contract basis. ALS TDF began creating our own core lab with the acquisition of a Thermo Electron quadruple mass spectrometer in 2005.

As Director of Mass Spectrometry, Nels brings a wealth of experience to ALS TDF. For more than 20 years, he performed and directed research at several major corporations including Dow Chemical and Springborn Smithers Laboratories. Nels received his PhD from the Northern Illinois University and has co-authored nearly 30 research articles and book chapters.

In the course of his research, Nels has analyzed and detected hundreds of drug compounds. He is excited that his new work will more directly benefit patients. “I appreciate using my experience to help discover drugs and therapies that will increase the length and quality of life of a person with ALS,” he says.

Nels will work closely with Fernando Vieira, ALS TDF’s animal surgeon, and the team that runs the animal studies.

In addition to measuring drug level, the mass spectrometer will provide our researchers with a greater understanding of how drugs penetrate the mouse spine and tissues. There is a lack of published data on the ability of potential therapeutics to reach the main site of

CONTINUED ON PAGE 13...

Need an Answer? Ask Our New Treatment Investigator

Got questions about info you found on the Web? Hear about a patient who’s trying something unusual? The person to ask is Dr. John McCarty. John works at ALS TDF, and his job is to know about every new treatment idea — and get to the bottom of it.

On any given day, John is researching stem cells in China, bee stings in Florida and the connections between ALS and other diseases that have been overlooked. Whether it’s a Chinese herb, a new therapy we’re testing, or an offbeat theory, John is on call, ready to provide the basic data to help guide your decisions.

With more than 20 years in biology research, including basic and academic research and applied biotechnology development, John is an invaluable resource to the ALS TDF community. He provides access to broad-based, credible scientific knowledge outside the mainstream, a service patients have long desperately needed.

Dr. McCarty can be reached at jmccarty@als.net or 617-441-7214.
In Our Lab

KDI

A published study suggests that KDI, a fragment of the laminin protein, promotes functional regeneration of severed rat spinal cords. This news generated significant interest in the ALS community, especially on our Web forum. With such studies there's the obvious connection to ALS via spinal nerve damage, though efficacy for acute injuries may not translate well to chronic degenerative diseases.

In response, ALS TDF promptly fast-tracked the compound as an ALS mouse study. The results of that study are now in: KDI shows no efficacy in symptom onset or progression in the mouse ALS model at the tested, direct-spinal dosage.

ALS TDF is best qualified to evaluate efficacy of KDI as a potential ALS treatment. Our scientists have perfected a technique for delivering therapeutic compounds directly to the spinal fluid in mice; a technique routinely performed only in our facility in ALS mouse studies.

Because KDI has not been developed in a traditional drug development pathway — where a drug's distribution and metabolism are better controlled — direct spine delivery is critical. As a simple tri-peptide molecule, KDI wouldn't be expected to survive well in the blood, or cross the blood-brain barrier to reach the spine and brain.

In the study, we based our initial dosage of 0.6 ug/day on previous dosing in rat studies (~ 6 ug/day), correcting for rats having a 10-fold greater CNS volume (brain + spinal cord) than mice. The lower dosage in the mouse spine should result in similar initial concentrations of KDI as in the initial rat study.

We still need to analyze tissue samples from mice treated with KDI to understand whether the compound actually penetrated the target spinal tissue, and if so, how much. (Our recently acquired mass spectrometer core should allow us to do the analysis in-house.)

KDI Biology: KDI is literally a small, three amino acid (K for lysine; D for aspartic acid; I for isoleucine) fragment of a much larger protein called laminin. As shown in the figure, laminin-1 is a large complex protein, itself composed of three protein
subunits, laminin alpha, beta, and gamma. It is this gamma-1 subunit (which is more than 1,600 amino acids long) that naturally contains the tri-peptide sequence ‘KDI’ towards one end.

As a class of proteins, laminins are major components of membranes and other sponge-like materials. These membranes form structures on which cells and organs are oriented. As such, they are critical for nerve growth and function. Laminins may play a role in the mechanism by which motor neuron axons are guided to grow in finding their corresponding muscle cells. Therefore, laminins, or fragments of laminins, have the potential to be interesting in understanding neural disease biology and could potentially play a role in recovery therapies.

Based on our comprehensive 48-animal study — and the difficulty in translating acute therapeutics for chronic disease — there is no indication that KDI will prove effective as a therapy for ALS. We have no plans to explore KDI further.

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1 Wiksten, et al. J Neursci Res. 2004 Nov 1;78(3):403-10 Regeneration of adult rat spinal cord is promoted by the soluble KDI domain of gamma1 laminin.
FasterCures Takes on the System

ALS TDF has joined forces with FasterCures, a Washington, DC advocacy group dedicated to speeding the process of discovery and clinical development of new therapies for treating deadly and debilitating diseases. In other words, “saving lives by saving time.”

FasterCures brings together industry leaders and visionaries, including ALS TDF d’Arbeloff Founding Director James Heywood, to work to remove key barriers to progress: government regulation, lack of industry standards and intellectual property restrictions.

Heywood shared his vision at the group’s Summit on Innovation in Disease Research, and is actively involved in TRAIN – The Research Acceleration and Innovation Network — a group of more than two dozen medical research foundations working to standardize data collection practices to increase collaboration and sharing.

“After years of feeling like we’re the only ones who felt that the system isn’t working, to work with a great group of professionals who are committed to improving the way things are done is an honor,” says Heywood.

Like ALS TDF, FasterCures was inspired by leaders who know the ravages of disease — and the dysfunction of the system — first hand. It’s an outgrowth of the Prostate Cancer Foundation, which Michael Milken founded in 1993 when he was diagnosed with the disease.

Other FasterCures initiatives include the development of a National Health Information Network (NHIN), and the use of electronic medical records (EMR) to speed research processes. This spring, FasterCures will launch BioBank Central, a Web portal connecting the global biobank community; the first step in standardizing collection procedures for tissue samples. For more information, visit www.fastercures.com

ALS TDF’S VISION

We envision a future where patients no longer die from ALS and where today’s patients are alive, well, and enjoying the company of their children and grandchildren.

We envision a future where treatments are developed for diseases based on their ability to save and improve human lives, not their potential to make profit. In this future we envision a Center where research science is re-connected to patients by bringing together patients, doctors, and researchers to openly share their findings, knowledge, and insight, and where that information is made available to the world. We envision a future where this model has expanded and changed the healthcare system into one that strives and succeeds at effectively seeking treatments for all diseases.
Dr. Peter Lansbury
ALS TDF Scientific Advisory Board Member Spotlight

Dr. Peter Lansbury has been an invaluable and engaged member of the ALS TDF Scientific Advisory Board (SAB) since its inception in 2003. As a member of the SAB, Dr. Lansbury provides scientific advice on a wide variety of matters concerning scientific program policy, future research direction as well as concept review of program initiatives. Dr. Lansbury is one of seven internationally renowned scientists and clinicians who contribute their time and expertise to the discovery and development of therapies at ALS TDF.

Dr. Lansbury received his bachelor’s degree from Princeton University with honors in chemistry in 1980 and his doctorate in organic chemistry from Harvard University in 1985, working with Nobel Laureate E. J. Corey. After a postdoctoral fellowship with the late Tom Kaiser at Rockefeller University, he joined the faculty of Massachusetts Institute of Technology as an assistant professor of chemistry in 1988. He moved to his present position in 1996 as Professor of Neurology at Harvard Medical School.

“Lansbury is an invaluable mentor and partner in our work. His pragmatic approach coupled with his expertise in chemistry and drug discovery make for a very powerful cooperative relationship. Peter is one of the leaders in the world of neurological research,” says Sean Scott, ALS TDF’s Vice President of Drug Development.

“My research career in academia has been dedicated to understanding the mechanisms that underlie neurodegenerative diseases like Alzheimer’s, Parkinson’s and, more recently, ALS. I have been increasingly frustrated by the fact that, although great strides were being made in basic science, those advances were not improving the lives of patients,” says Dr. Lansbury.

“ALS TDF is taking action to correct this problem. What is required is creative thinking, and I have found that the ALS TDF team has it in abundance. I hope that my involvement in ALS TDF will help create additional initiatives that will harness the power of science and send ALS the way of polio.”

Dr. Lansbury is director of the Brigham and Women’s Hospital Morris K. Udall Parkinson’s Disease Research Center of Excellence. He is a member of the steering committee of the Harvard Center for Neurodegeneration and Repair and co-founder and chair of the Laboratory for Drug Discovery in Neurodegeneration at Harvard University.

“I hope that my involvement in ALS TDF will help to create additional initiatives that will harness the power of science and send ALS the way of polio.” — Dr. Peter Lansbury
The 2005 Leadership Award winners were honored at a dinner during the 2005 Leadership Summit. It is our privilege to publish the winners and their stories here.

Recently, three of the award recipients passed away from complications of ALS. Joe Shambo, Steve Lewis, and Matt Dowd have each left their mark on the ALS community. They are remembered for their courage, kindness and fighting spirits.

**THE STEPHEN HEYWOOD PATIENTS TODAY AWARD**

Presented to a special member of the ALS community who has tirelessly proven to be a strong advocate for research and awareness.

**Joe Shambo** was a selfless individual who inspired others to ask questions and ensured that focus remained on patients. Joe was a true advocate and was instrumental in securing funding from the state of Massachusetts for ALS research. Privately, Joe always encouraged his family to “never give up, and appreciate even the smallest things in life.”

**Matt Dowd** was a vital force in the ALS community. Intelligent, strong, and steady in the face of this disease, Matt battled ALS with dignity. He was a tireless advocate for other patients, researchers, and families. Matt’s personal mantra, “Do not go gentle into that good night,” continues to be an inspiration to all who knew him.
THE STEPHEN MILNE ADVENTUROUS SPIRIT AWARD
Given to the person who consistently and bravely explores new ground in fighting the disease and raising awareness.

Steve Lewis was a person of incredible spirit and insight in his fight against ALS. His honor, determination, and hope had a quiet power that held the attention of many. He lost his battle with ALS just two days after receiving this award in person. Steve will be remembered as a kind and good friend to the staff, friends, and family of ALS TDF and will be dearly missed.

THE FRAN DELANEY CHALLENGE AND RESPECT AWARD
The recipient of this award continually questions the science and research surrounding ALS and drives new initiatives to battle the disease.

Faye Magneson has an invaluable ability to gather a unique and powerful constituency in the fight against ALS. Highly respected in her community and among researchers at ALS TDF, Faye continually challenges the research and demands answers for ALS patients. She is a remarkable woman who not only fights for herself, but for the entire ALS community.

THE MARY LOU KRAUSENECK COURAGE AND LOVE AWARD
Presented to a strong spirit who, despite all obstacles, has created a foundation of hope by maintaining a passion for life.

Amy Whipple has unwavering passion in uniting her community to fight ALS in honor of her aunt, Mary Lou. Amy's spirit is unmatched and could truly move mountains — her courage and love have inspired an entire community to join the fight.

2006 nomination forms are available at www.als.net. All nominations are due by May 15, 2006.

NOMINATE A LEADER!

James Heywood and Steve Lewis
Molly Cotter and Amy Whipple
Jaime Berton, Matthew Whipple and Wendy Heywood
Jenny Huntington lived a few doors down from the Heywood family in Newton when Stephen Heywood was diagnosed. When the family launched the ALS Therapy Development Foundation, her concern and desire to comfort friends and neighbors became an intense interest in the strategy that started in the basement of the Heywood family home. Huntington offered herself to the burgeoning effort and was an invaluable supporter from the start. Longtime educator and advocate for environmental and health issues, Huntington's knowledge and leadership became a cornerstone of what is now a model nonprofit research effort.

This March, ALS TDF is honored to announce our summer high school internship program will be named for Jenny Huntington. The Jenny Huntington Internship Program will provide high school students with a great opportunity to engage first-hand in real scientific research or learn the fundamentals of the nonprofit business.

Jenny Huntington (right) with grandchildren Zoe and Sam.
institute. There during good times and bad, Huntington now serves on both the ALS TDF Board of Directors and is a regular, active participant in our community.

“When Jenny Huntington agreed to be on our Board as we were forming ALS TDF, we were thrilled and honored,” say Peggy and John Heywood. “She brought to our fledgling enterprise a wealth of life experience. Her great personal integrity, wisdom, generous spirit, optimism and unstinting hard work have been a constant for the Foundation. We feel blessed by her friendship.”

Supporting the foundation in any way possible, Jenny has influenced the fabric of the ALS TDF community in so many ways. Each summer, Newton North High School provides interns to the Foundation for the laboratory and operations department, giving the Foundation some of its finest repeat interns and providing students with a chance to learn. Our full-time staff also responds appreciatively as Jenny is the first to sit down at gatherings and ask how work is, or school or project work. Jenny nurtures the spirit of ALS TDF and strengthens us for the future.

Jenny’s teaching career began in 1962 and she has taught in such far-reaching places as Nigeria. She was elected to the Newton School Committee and serves as a member of the Visiting Committee for the Perkins School for the Blind. Huntington, who is particularly concerned with matters concerning health care and the environment, also served on the Boards for Harvard Community Health Board of Directors, the Alaska Conservation Foundation, and the Northern Forest Center in New Hampshire. She has also been president of the Appalachian Mountain Club. She will be retiring as Principal from Newton North this spring after seven years in Newton and 27 years of service.

Extra Hands for ALS is an innovative national service program that matches young adult volunteers with people who have ALS. Young volunteers gain community service and leadership experience; ALS families gain practical, non-medical support such as light house cleaning, errands, special projects or just companionship. Extra Hands empowers ALS families by offering them a chance to educate a new generation of advocates about ALS. Extra Hands currently operates in Boston, St. Louis, Boise, Denver, Dallas-Fort Worth, Los Angeles, Orange County, and San Francisco. Please visit www.extrahands.org or call 847-441-5940.
Join the Tri-State Trek Ride to End ALS

Mark your calendar for the 2006 Tri-State Trek Ride

On July 17, 2005, cyclists from across the country came together for the third annual Tri-State Trek. Three days and 270 miles later, through Massachusetts, Connecticut and New York, the pack pedaled into White Plains, New York to the most spectacular finish in the event’s short history.

A fundraiser designed to push the human spirit, the Tri-State Trek was built to increase the public’s knowledge of ALS and to raise money for ALS TDF. The fundraising goal in 2006 is $165,000, about 50 percent more than what was raised last year, and a 300 percent increase from what was raised in 2003. Event organizers are confident they will exceed their goal.

This year will mark the Trek’s fourth year, a significant number in the ALS community (Lou Gehrig’s jersey number), and participants who have ridden all four years will be recognized at the second overnight in New Haven, CT, as they reach their 2,000th mile.

It’s a true cyclist’s course — challenging, diverse, scenic, and beautiful — but the Trek is designed to be completed by anyone willing to train. Everyone knows how to ride a bike, and while some of the event’s riders are experienced cyclists, many will do their first century (100 mile day) on Saturday’s ride.

This year the Trek will offer one-day routes on Friday and Sunday. Friday is a 60 mile cruise to the lunch stop in Webster, Mass, and Sunday is a more challenging 75 mile ride through the foothills of Fairfield County, Conn and Westchester County, New York. On Sunday, cyclists will ride in honor of ALS patient Jon ‘Blazeman’ Blais. Remembering Jon’s incredible strength and courage through 2005 Ironman Hawaii, riders will climb some of the steepest hills on the event and roll through the closed streets of White Plains with a full police escort.

The dates for the 2006 TST are July 21-23. To ride, volunteer or support a rider visit the Web site at www.tristatetrek.com.

FOR MORE INFORMATION:

Join Us - Ride to End ALS
ALS Patient Finishes Ironman

“I wasn’t going to be the guy that tried to complete the Ironman, I was going to be the guy who finished it with ALS.” — Jon Blais

What better symbol for modern day ALS than the Blazeman? Patient, poet, athlete, inspiration. Jon Blais wouldn’t just try to finish a triathalon; he was determined to complete the ultimate Ironman triathalon — as a patient with ALS.

Having finished several triathalons, Blaze had always dreamed of competing at the Ironman World Championship in Kona, Hawaii. And nothing would stop him. Last year, Blaze accomplished this unbelievable feat — in just over 16 hours.

“You can see it in his eyes, the passion to end ALS, the very disease that’s claiming his own body. What a potent symbol for the ALS TDF lab, someone who takes on a seemingly insurmountable task and fights to get through it every single moment,” says James Heywood, d’Arbeloff Founding Director.

Blaze’s story of determination and hope was profiled by NBC last November. Since, Blaze has focused all his energy and passion into helping ALS TDF find a cure.

“When Blaze comes in the building, you can feel the energy rise,” Heywood says. “Here’s a guy who completed the Ironman. What an honor to have him as part of our team. He’s giving us new reason to fight.”

FOR MORE INFORMATION:

You can read more about Jon and his efforts by visiting his Web site www.alswarriorpoet.com.

MASS SPECTROMETRY CONTINUED FROM PAGE 3...

injury in the ALS mouse model, the lumbar spinal tissue. Regular analysis will allow better predictions on drug penetration in the spine — knowledge that will benefit the entire ALS research community.

Last, a crucial need in ALS research is the availability of biomarkers to monitor disease development and progression. Research on biomarkers represents an additional area of development for mass spectrum analysis. Optimally, such markers, consisting of either small molecules or proteins, will be detectable in readily accessible tissue such as blood or spinal fluid.
An International Fight

Roby Molnar brings international flare to our fundraising efforts at ALS TDF. From his home in Zurich, Switzerland, Roby, with his wife Nadja, has worked tirelessly over the last year to raise money for ALS TDF’s Family & Friends Community.

After his diagnosis in June of 2004, Roby decided to create his own charitable foundation called StopALS and has since donated nearly $30,000 to ALS TDF’s research efforts. He also maintains the Web site www.enjoyyourlife.ch, a testament to his enduring commitment to live his life completely and spend his time making worthwhile contributions to the ALS community. “I know [a cure] is out there. It’s simply a matter of finding it,” says Roby.

For more information, please visit www.stopals.ch.

Volunteer Spotlight

Ann Trerice is part of the “band of angels” who work behind the scenes for the Mary Lou Krauseneck Fund. Ann single-handedly packages more than 400 auction items into gorgeous gift baskets for the “A Passion for Life” Benefit and Celebration each year. This task would be an overwhelming one for anyone, but Ann handles it with love and grace.

Over the last year, Jody Freid has provided phenomenal support to the Friends for Faye campaign. A close friend of patient Faye Magneson, Jody took it upon herself to organize the first annual Friends for Faye Golf Tournament and Tribute in South Bend, Indiana, which raised nearly $400,000 for ALS TDF.

Ann DeLuca is one of ALS TDF’s newest volunteers. In November 2005 Ann opened up her home in Lutz, Florida and hosted a fantastic wine tasting event that raised nearly $15,000. As a close friend of patient Doug McGuiness, Ann is dedicated to making a difference in ALS research and we are happy to have her as part of our team.

Mary Okerson is one of the many volunteers who, year after year, help to make the Stephen Milne Society such a success. For the past four years, Mary has headed up the Society’s golf tournament in Silver Spring, Maryland. Mary’s efforts have been vital to launching the campaign past its $1 million mark.

Ann Trerice

Jody Freid

Ann DeLuca

Mary Okerson
Documentary “So Much So Fast” Premiers at Sundance

ALS TDF is a unique place. So unique it’s attracted attention and press for the processes and techniques we’ve developed in trying to find a treatment. The documentary, So Much So Fast, which premiered in February at the Sundance Film Festival, is perhaps the best expression of our people and passion.

Newton, Mass., filmmakers Steven Ascher and Jeanne Jordan — best known for their 1995 film Troublesome Creek — shot the movie over a five-year period, chronicling the progression of Stephen’s illness and the birth of ALS TDF.

“It's been an honor to have Steve and Jeanne make this film,” says James Heywood, D’Arbeloff Founding Director. “Their passion and dedication to their own work mirrors our own. We’re proud to have this film showcase our beginning.”

For the film’s Sundance debut, the entire Heywood family — including Stephen, the ventilator, the power wheelchair and all the trappings — went to the film festival in Utah. At the end of the film, the audience gave Stephen a standing ovation.

“With Stephen’s disease today it’s hard to meet him,” says Heywood. “This film gives everyone a chance to meet my brother as I know him.”

“Being at the premier meant so much to me and the entire family. It was worth the journey,” says Stephen Heywood.

So Much So Fast is not yet in distribution. For updates on where it will be shown, visit www.somuchsofast.com

“The Heywoods, for all their trouble, are never portrayed as pitiful, but rather as men of existential nobility.”

— John Anderson, Variety
PGA TOUR PLAYERS CONTINUE TO PLAY KEY ROLE

Throughout 2005, Driving 4 Life received continuous financial support from the PGA TOUR family. Driving 4 Life received gifts from three golfers who played in the Crestor Charity Challenge: Luke Donald (Buick Invitational), Olin Browne (Deutsche Bank Championship) and K.J. Choi (Chrysler Classic of Greensboro).

Driving 4 Life also received a very special holiday gift from a long-time and dear friend, Freddie Couples, when he named Driving 4 Life to receive his portion of the winnings from the 2005 Presidents Cup.

More than three dozen PGA TOUR players also donated items, cash and their time to Driving 4 Life in 2005. You will soon see a list of those that gave in 2005 online as part of the new “19th Hole” on the Driving 4 Life Web site.

Driving 4 Life events raised $1.5 million in 2005, surpassing a $3 million dollar milestone in less than three years!

Special thanks to our event sponsors, organizers, committees, volunteers and participants who made it possible, and to Jamie Heywood, Sean Scott and the amazing research team at ALS TDF for making our fundraising necessary and providing us hope by conducting the best research on the planet!

I would also like to thank Dr. Robert Hariri and Celgene Cellular Therapeutics for acting as title sponsor for the Driving 4 Life Invitational and making it a huge success for the past two years. Dr. Hariri and his wife Maggie opened their lovely home to staff members, event committee members and local ALS patients last September for a pre-event cocktail party. We’re truly grateful for Dr. and Mrs. Hariri’s continued support and dedication.

As Driving 4 Life grows and expands to bring even more funding to research, we want you all to know how wonderful it is to be allied with such an amazing network of individuals who give of themselves so generously. You are the foundation of a campaign that will one day raise $20, 60 or 100 million per year. Hats off to all of you who are doing whatever it takes to find the cure.

Kim Julian
Founder,
Driving 4 Life

FOR MORE INFORMATION:

www.driving4life.org
617.441.7295
Driving 4 Life Across the Country

September 12, 2005
2nd Annual Driving 4 Life Invitational :: Bedminster, NJ

> Chris Martin, seated, displays the Driving 4 Life Courage Award. Standing from left to right; ALS TDF CEO James Heywood, President of Celgene Robert Hariri, M.D. and Chris’ wife Jackie.

December 3, 2005
3rd Annual Driving 4 Life Golf Tournament :: Westin, FL

> Event co-chairs Herb Schwartz and Dave Camken, shown above, display a pin flag autographed by ALS TDF staff in recognition of their leadership and hard work.

January 9, 2006
Russ Lyon Driving 4 Life Charity Golf Tournament :: Glendale, AZ

> Golfers enjoyed friendly competition at this first time event in sunny Arizona.

STEP UP TO THE TEE

Most of the $3 million raised to date can be directly attributed to families and friends of ALS patients who launch their own golf tournaments and other fundraisers as part of the Driving 4 Life campaign. Together, we’ve created one of best-supported golf fundraising systems in the world, and are looking for new events in all areas of the country. Families and friends, step up to the tee and become part of our greatest round ever. Please call Molly Cotter at 617.441.7249 to learn how easy it is to make a big difference.

COMING SOON TO OUR WEB SITE

Significant upgrades to our Web site will make more Driving 4 Life events possible, effective and far-reaching. You’ll be able to announce your event, track its development and get direct and personalized support from our team as well as other event organizers. The 19th Hole is where we celebrate all those who’ve contributed to this campaign; a source of pride for years to come. Continue to visit us online for the latest ways to stay involved at www.driving4life.org

BE PART OF DRIVING 4 LIFE

With nearly 30 events on our calendar this year, there’s an opportunity for you to get involved right in your own community. Our goal is to raise the next $3 million in half the time, so if you can’t make it out to the course, donate online or by calling 617.441.7200.
THREE OF THE WORLD’S TOP COURSES TO HOST
DRIVING 4 LIFE SIGNATURE SERIES IN 2006

Driving 4 Life joins three of the world’s best golf courses to expand the Signature Series to three events this year, two of which will be held at PGA TOUR host sites in the cities of Boston and Los Angeles.

The Driving 4 Life Invitational held at Trump National in Bedminster New Jersey for the past 2 years has become the pinnacle of our fundraising efforts. With the addition of the Quest for a cure Open at the TPC of Boston and the Western Invitational at Riviera Country Club of Los Angeles we continue to grow the campaign and maximize ALS research funding.

If you’re interested in hosting your own Driving 4 Life event, or getting involved and helping out with one of the signature series events, please email Rob at rgoldstein@als.net or call 617-441-7295.

Special Thanks to:

PLAY THE WORLD’S BEST, SUPPORT THE WORLD’S BEST
DRIVING 4 LIFE SIGNATURE SERIES EVENT SCHEDULE FOR 2006

TO RECEIVE AN INVITATION TO A SIGNATURE SERIES EVENT, PLEASE SEND A REQUEST VIA EMAIL DRIVING4LIFE@ALS.NET
2005 Events
ALS TDF would like to thank the volunteers who have worked tirelessly in 2005 to host events that fund ALS research.

West Hartford Kitchen Tour
Kitchen Bath & Design Consultants, LLC
Weathersfield, CT

Legends of Tennis
Marathon, FL

The ALS Family Charitable Foundation
9th Annual Cliffwalk
Bourne, MA

The Julian, 4th Annual
Branson, MO

4th Annual "A Passion for Life"
Benefit and Celebration
Chesterfield Twp, MI

Gino Torretta's Celebrity Blue Tee Weekend
Doral, FL

St. Patrick's Day Walk/Run
Detroit, MI

Chris Martin Golf Tournament
Port St. Lucie, FL

Coins for A Cure
Erie, PA

The 4th Annual Steve Carlin ALS Research and Assistance Fund Charity Golf
Fayetteville, NC

A Cure is Coming!
Boston, MA

Shoot for a Cure
Syracuse, NY

Rockin' for a Cure
Madison, WI

Bruce Edwards Memorial Golf Tournament
Vero Beach, FL

2nd Annual Dave Haslup ALS Golf Tournament
Easton, MD

Larry Ellis Driving 4 Life Golf Tournament
Crofton, MD

Dick Sanderson Driving 4 Life Golf Event
Davidson, NC

Teaching for a Cure
Chapel Hill, NC

The Blue Cross Broad Street Run
Philadelphia, PA

Lee Blaskovich Memorial Golf Outing
Oak Brook, IL

Bruce Edwards Driving 4 Life Golf Event
Prescott, AZ

Medved's Father's Day 5k to Cure ALS
Rochester, NY

The Jeff Julian Driving 4 Life Golf Tournament
Newbury, NH

Faye Magneson Golf Tournament and Tribute
South Bend, IL

Jim Slovik Memorial Golf Outing
Hawley, PA

Driving 4 Life Golf Marathon
Danbury, NH

10th Annual ALS TDF Golf Tournament
Winchendon, MA

Donate your Score Days
Chester, IN

NCPGA/AGA Father Son Tournament
Havelton, PA

Home to Home Event
Nokesville, VA

Steps to Make a Difference
Madison, WI

2nd Annual Stanfield Family Par 3 Shootout
Tulsa, OK

Somerville Arts Festival
Somerville, MA

Tri State Trek
Boston, MA to White Plains, NY

Friends of Steve Golf Tournament
Erie, PA

Hopkins Family Movie Day
Chester, NY

Easton Concrete Golf Tourney
Easton, MA

Golf 4 ALS
Hampden, MA

Teach to Fight ALS
Long Island, NY

4th Annual Stoddard Family Driving 4 Life Event
Stockton, IL

The Rene Bourassa Memorial Golf Tourney
Groton, CT

Go To Bed Laughing ALS Benefit 2005
Merserberg, PA

4th Annual Jim Raspanti Golf Outing
Pittsburgh, PA

A Walk with Passion
Sterling Heights, MI

Jeff Hadley Day
Killington, VT

Pittsburgh Steelers Raffle
Pittsburgh, PA

3rd Annual Night of Rhythm and Hope
Pittsburgh, PA

2nd Annual Driving 4 Life Invitational
Bedminster, NJ

Matt's Challenge 4 Life Invitational
Walpole, MA

Stafne Family & Friends Affair
Golf Tournament
Minneapolis, MN

Marine Corps Marathon
Washington, DC

1st Annual Ronnie Abdinoor Memorial Golf Tournament
Methuen, MA

BAA Half Marathon
Boston, MA

Bruce Edwards and Tom Becker Golf Tournament
Jacksonville, FL

Al's Speakeasy
Cambridge, MA

Beth Douglass NYC 1/2 Marathon
New York, NY

14th Annual HMs Host Classic
Tampa Bay, FL

PGA Tour Superstore World Amateur
Myrtle Beach, SC

Stephen Milne Society Maryland Golf Tournament
Silver Spring, MD

Driving 4 Life Wine Tasting
Lutz, FL

ALS Soccer Cup
Newburyport, MA

Coins for a Cure
St. Louis, MO

Douglass Family Christmas Tree Sale
Fairhaven, MA

2nd Annual Trike-athon
Newton, MA

Driving 4 Life Golf Tournament
Westin, FL

THANK YOU!

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Coming to You
(MARCH - JULY)

March 6th
Gino Toretta's Celebrity Blue Tee weekend
Miami, FL

+ March 31st
5th Annual "A Passion for Life" Benefit and Celebration Chesterfield Township, MI

April 24th
Larry Ellis Driving 4 Life Golf Tournament Crofton, MD

+ April 7th
Lynn Capria Memorial Golf Tournament Clermont, FL

+ April 22nd
A Cure Is Coming! Boston, MA

+ April 27th
Dick Sanderson Driving 4 Life Golf Tournament Davidson, NC

+ April 29th
Rockin for a Cure Madison, WI

+ May 6th
3rd Annual Dave Haslup/ Lou Gehrig A.S.F. Golf Tournament Easton, MD

+ May 8th
Quest for a Cure Open Norton, MA

+ May 12th
Lee Blaskovich Memorial Golf Addison, IL

+ May 13th
Bruce Edwards Driving 4 Life Golf Tournament Prescott, AZ

+ June 3rd
Teach to Fight ALS Long Island, NY

+ June 5th
Rick Bowling Invitationals Pittsburgh, PA

+ June 8th
Cyndee Luedecking Memorial Golf Tournament Michigan Center, MI

+ June 23rd
Haley/Tucker Golf Tournament Winchendon, MA

+ June 26th
Friends for Faye Tournament South Bend, IN

+ July 2nd
Donate Your Score Chesterton, IN

+ July 7th
17th Annual Chris Stoikos Memorial Fight against ALS Golf Tournament Markham, Canada

+ July 10th
Friends of Steve Outing Erie, PA

For more information on any of these events, go to our website: www.als.net