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**FOR IMMEDIATE RELEASE**

## ALS Patients and Researchers Unite in Boston for 4th Annual Leadership Summit

*Panel of ALS Researchers to Present and Consider the Latest Therapeutic Approaches*

**Cambridge, Mass. – September 24, 2008** – The ALS Therapy Development Institute (ALS TDI) announced the line-up for its upcoming, annual ALS research symposium, part of the fourth annual ALS TDI Leadership Summit. The symposium will take place this October 20<sup>th</sup> at the Beacon Hill Holiday Inn in Boston, Mass. A diverse panel of scientists will provide presentations on the development of effective treatments, or a cure, for amyotrophic lateral sclerosis (ALS, commonly known as Lou Gehrig’s disease). After each presentation, audience members are invited to offer comments and ask questions regarding the research. Several of the guest speakers will participate in a panel between the morning and afternoon sessions. All parts of this event are free and open to the public.

“There is a need in the ALS community for openness and directness when it comes to describing what is done with all the monies donated for research. Providing unbiased access to information and researchers is one of the pillars of the ALS TDI philosophy. This annual event provides a unique setting for patients and researchers to connect in pursuit of a shared goal,” said John McCarty, Ph.D., Director of Therapeutic Investigation at ALS TDI.



The following is a list of confirmed researchers and proposed presentation topics:

- “*Our Plan, Our Progress, Your Lab*,” Sean Scott, President, *ALS TDI*, Cambridge, Mass.
- “*The MDA Commitment*,” Sharon Hesterlee, Ph.D., Vice President for Translational Research, *Muscular Dystrophy Association*, Tucson, Ariz.;
- “*Towards defining the molecular basis of ALS: clues from TDP-43*,” Michael J. Strong, M.D., Co-Chair, Department of Clinical Neurological Sciences, Arthur J. Hudson Chair in ALS Research, *London Health Sciences Centre*, London, Ontario, Canada;
- “*Development of an immunotherapy for ALS*,” Jean-Pierre Julien, Ph.D., Professor, *Laval University*, Quebec, Quebec City, Canada;
- “*Developing an Aptamer Library for ALS*,” G. Thomas Caltagirone, Ph.D., President & CEO, *Aptagen, LLC*, Jacobus, Penn.;
- “*A Comprehensive Approach to Communication Systems for ALS Patients and their Families*,” Troy Jurgenson, Co-Founder, *Speak Up ALS*, Corona del Mar, Calif.;
- “*The Genomic and Proteomic Approach to ALS Research*,” Steve Perrin, Ph.D., Chief Scientific Officer, *ALS TDI*;
- “*Information Resources for ALS Patients and Researchers*,” John McCarty, Ph.D., Director of Therapeutic Investigation, *ALS TDI*;
- “*The Role of Inflammation in ALS*,” Stan Appel, M.D., Co-Founder & Co-Director, *Methodist Neurological Institute*, Houston, Texas.

The ALS TDI Leadership Summit is a two-day event aimed at providing a forum for the exploration of the past, present and future of research into an effective treatment for ALS. The event is designed to provide a forum for open discussions between researchers, patients and their families. The first day of the event consists of guided tours of the 16,000 square-foot translational research facility in Cambridge, Mass., where the bulk of the Institute’s research team is located. There are 30 scientists and technicians that work full-time at the Institute, the largest of its kind, focused exclusively on developing an effective treatment and cure for ALS. This event is made possible in part through a fundraising partnership between ALS TDI, MDA, and its Augie’s Quest initiative. The historic, three-year, \$36 million funding agreement began at the start of 2007 and has played an intricate role in the expansion and acceleration of research efforts at ALS TDI and elsewhere.

The Research Symposium takes place between 8:00am and 5:00pm at the Beacon Hill Holiday Inn, and will be followed by a dinner hosted by the scientific staff of ALS TDI. At the end of the Summit, four awards will be presented to members of the ALS community that have contributed in significant ways to furthering ALS research

and being advocates in their community. To attend this free day-long event, pre-registration is available online at <http://www.als.net/summit> or by calling Vanessa Plant at 617-441-7230.

#### About the ALS Therapy Development Institute

The ALS Therapy Development Institute (ALS TDI) ([www.als.net](http://www.als.net)), based in Cambridge, Mass., operates the world's largest research and development program focused exclusively on ALS. The Institute has a staff of more than 30 scientists and research technicians, working on behalf of ALS patients to discover and advance novel therapeutics for treating, and ultimately curing, ALS. The nonprofit biotechnology institute excels in identifying novel disease targets, discovering compounds that may act against these targets, and screening potential treatments for clinical development.

#### About Augie's Quest

Fitness pioneer Augie Nieto started Augie's Quest ([www.augiesquest.org](http://www.augiesquest.org)) in conjunction with MDA's ALS Division. Nieto is co-founder and former president of Life Fitness of Chicago, and chairman of Octane Fitness. He and his wife, Lynne, serve as co-chairpersons of MDA's ALS Division. Nieto received a diagnosis of ALS in March 2005.

#### About MDA

MDA ([www.mda.org](http://www.mda.org)) is the world's largest provider of ALS services and funder of ALS research. Over the years, it has expended \$230 million in this effort. It operated 225 clinics across the county, 38 of which are ALS-specific research and care centers.

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