

ALS Forum e-Newsletter Volume 70

September 13, 2012

Visit the ALS Forum website to read the complete stories featured in this e-newsletter. Please forward this e-newsletter to friends and colleagues who may be interested in learning more about ALS.

**Resources:**

Upcoming Workshop  
 October 2 and 3: [Applying to the NIH SBIR Phase I Program for First-Time Applicants](#)

**Upcoming Registration Deadline:**

[Register Now for the 23rd International Symposium on ALS/MND](#), December 5-7, 2012: Chicago, IL.  
[The program was just released.](#)

**Upcoming Meetings:**

September 21-22, 2012:  
 Quebec, Canada: [Annual Foundation Andre-Delambre ALS Symposium: Causes and Therapeutic Perspectives](#)

October 2, 2012:  
 Rockland, MD: [3rd Annual Conference on Clinical Research for Rare Diseases](#)

October 3-6, 2012:  
 Orlando, FL: [American Association of](#)

**Research News**[Pro Football Players Over Four Times More Likely to Develop ALS](#)

A recent study, the findings of which were published September 5 online in *Neurology*, revealed that NFL players are at a four times higher risk of developing Alzheimer's disease and ALS than people in the general population. The study surveyed health records from over 3,400 retired NFL players who played at least five seasons between 1959 and 1988. Of these players, 334 had passed away, and a statistically significant number of them had passed away from neurodegenerative disease. Of those that passed away, the incidence of dementia and Alzheimer's disease was 3.86-fold higher than the normal population. The incidence of ALS was even higher at 4.31-fold. Although, the study did not examine the direct relationship between traumatic brain injury and neurodegenerative disease, the researchers found that players in contact positions had a 4.74 times higher incidence of neurodegenerative disease than the average US male. The same day the findings were released, the league announced that it will be donating \$30 million to the National Institutes of Health to support research efforts to understand the link between traumatic brain injury and neurodegenerative diseases.

[MuSK May Mean Better Quality of Life for People with ALS](#)

It has been reported that loss of neuromuscular junctions (NMJs) is one of the earliest pathologies observed in ALS. In a recent article published in *Cell Reports*, researchers at the NYU School of Medicine reported that muscle skeletal receptor tyrosine kinase, MuSK, may help delay NMJ loss. When *MuSK* expression was increased 3-fold in an SOD1 G93A mouse, it delayed the onset of muscle denervation by nearly 40 days. Although *MuSK* overexpression was not linked to an increase in lifespan, targeting MuSK could provide a potential opportunity to improve quality of life for people with ALS if doing so allowed them to similarly maintain control of their muscles for longer. The ALS Forum previously reported on Dr. Steve Burden's Keystone presentation on MuSK's role in forming neuromuscular junctions in March. You can read a detailed summary of Dr. Burden's talk (the basis for the new paper) on the ALS Forum [here](#).

[Researchers Identify Genetic Region That Influences the Age of ALS Onset](#)

[Neuromuscular & Electrodiagnostic Medicine Annual Meeting](#)

October 7-9, 2012:  
Boston, MA: [American Neurological Association 2012 Annual Meeting](#)

**Training Program:**

[Interested in drug discovery and development for nervous system disorders? Apply to the NIH Blueprint-funded training program!](#)

Application deadline:  
October 1, 2012.

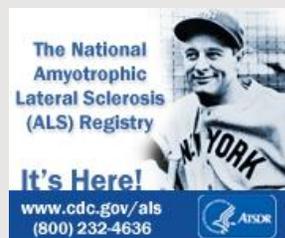
**Funding News:**

[MGH's Neurology Clinical Trials Unit Calls for ALS Clinical Trial](#)

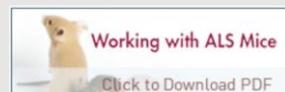
**Applications:** Application Due September 17, 2012

[2013 AAN Foundation ALS-Richard Olney, MD Clinician Scientist Development Three Year Award](#)

[MNDA PhD Studentship](#)



**Download your free copy:**



In a study published online in *Neurobiology of Aging* on September 7, the International Consortium on Amyotrophic Lateral Sclerosis Genetics (ALSGEN) reported the results of a meta-analysis of genome-wide association studies that included 4,243 people with ALS and 5,112 control individuals from 13 European ancestry cohorts. ALSGEN identified eight genomic regions that were statistically associated with ALS. Of these eight, six of these regions showed association with the age of ALS onset. The strongest locus associated with age of onset was found on chromosome 1 at SNP rs3011225. Individuals with this SNP developed ALS two and a half years earlier than people who did not have this SNP. These findings may provide important clues for understanding ALS progression.

**'Awakened' Transposons May Cause ALS**

A recent study published in *PLoS ONE* suggests that transposons may be linked to ALS and FTLN. Transposons are normally only active during neurogenesis, and are silenced after neurogenesis is complete. By mining deep sequencing datasets of gene expression profiles and protein-RNA interactions, the researchers found that TDP-43 binds RNA transcripts transcribed from transposon elements and may potentially have a role in silencing transposons. Although the details are not fully fleshed-out, the authors suggest that transposon deregulation may lead to ALS and FTLN. Although intriguing, these findings require further validation. Also, is there any link between this transposon hypothesis and the tantalizing hints around retroviruses and ALS?

**Drug News**

**[PrecisionMed Enrolls First Donor in ALS Registry](#)**

PrecisionMed, the leading commercial supplier of human cerebrospinal fluid (CSF), has enrolled their first donor in the PrecisionMed Amyotrophic Lateral Sclerosis (ALS) Registry. The PrecisionMed ALS Registry is a source of biological samples for purchase, including CSF, DNA, and RNA collected from people with ALS. PrecisionMed hopes to enroll 2,000 donors. With funding from the ALS Association, the [Northeast Amyotrophic Lateral Sclerosis Consortium \(NEALS\)](#) also provides free research access to a repository of CSF, blood, DNA, urine, serum and plasma collected from people with ALS. Both registries will be valuable for researchers, and hopefully will provide key insights that will lead to a discovery of a treatment and cure for ALS.

**[Quartz Bio - A New Biomarker Data Management and Analysis Company](#)**

Merck Serono recently launched a spin-off, Quartz Bio, which will provide biomarker data management and analysis services for pharmaceutical companies. Quartz Bio meets the developing needs of pharmaceutical companies, both in the drug development pipeline and once the drug is on the shelf. Biomarker analyses can help pharmaceutical companies design better clinical trials, because they can be used to predict which patients will respond to which therapies, potentially helping doctors tailor treatments to individual patients. This article emphasizes the enormous clinical importance of biomarkers, a major focus of Prize4Life's programmatic initiatives.

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FORUM



### [CVS/pharmacy's In-Store Fundraising Campaign Raises \\$5M for Research](#)

CVS/pharmacy's in-store Advancing Medical Research fundraising campaign brought in more than \$5 million dollars. Donations at the register were collected over a 5-weeks period from the end of May through June. The money will be split between ALS and cystic fibrosis research, and will also be used to improve the quality of life for people with these diseases. CVS/pharmacy has been raising funds for ALS research for more than 10 years and has already given over \$27 million to ALS research. CVS/pharmacy celebrated the results of their Advancing Medical Research campaign at Fenway Park where [Lucas Fox, a 9 year old from Indianapolis living with cystic fibrosis, threw out the first pitch at the Red Sox vs Toronto Blue Jays game on September 7.](#)

### [Cytokinetics Begins Phase IIb for Tirasemtiv](#)

Cytokinetics, Incorporated has initiated the Phase IIb study of tirasemtiv (formerly CK-2017357) in people with ALS. Cytokinetics plans to enroll around 400 people with ALS in the clinical trial. Those enrolled will either receive tirasemtiv or the placebo twice daily for three months. The trial will use the revised ALS Functional Rating Scale (ALSFRS-R) to assess changes from baseline in those receiving either tirasemtiv or the placebo. [In April, the FDA granted an orphan drug designation and fast track status to tirasemtiv for the potential treatment of ALS.](#)

The ALS Forum was developed by Prize4Life, Inc.  
P.O. Box 425783 Cambridge, MA 02142

[www.prize4life.org](http://www.prize4life.org)

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