



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:

The ALSGene tool:
www.ALSGene.org

The PRO-ACT Database:
www.ALSDatabase.org

[NEALS Biofluid Repository
Available to Researchers](#)

[NINDS Fibroblast
Repository](#)

[VABBB Tissue Request
Information Site](#)

Funding Opportunities:

[Blueprint
Neurotherapeutics Network
\(BPN\): SBIR Small
Molecule Drug Discovery
and Development for
Disorders of the Nervous
System \(U44\)](#). Applications
due October 21, 2014.

[NCATS Small Business
Contract
Funding](#). Applications
due November 5, 2014.

[EuroMOTOR Competitive
Call for Novel Therapies for
ALS](#)

Upcoming Meetings:

October 2014

Conference News

[Prize4Life Covers the Project MinE International Kick-off Meeting](#)

The [Project MinE](#) international kick-off meeting took place on September 8, 2014 in Amsterdam, Netherlands. Project MinE is a large scale research initiative with the goal to sequence and analyze genomes from 15,000 ALS patients and 7,500 controls in order to unravel the genetic basis for ALS. The aims of the meeting were to discuss international collaborations in ALS research in general and in Project MinE in particular, and to discuss the formation of a Project MinE consortium. Prize4Life-Israel's CEO Shay Rishoni and Chief Scientific Officer Dr. Neta Zach attended the meeting. Click [here](#) to read Dr. Zach's report on this dynamic event.

Research News

[ALSA Commits an Initial \\$21.7 Million of Ice Bucket Donations to Fund New Research Initiatives](#)

The [ALS Association \(ALSA\)](#) received over \$100 million in donations this summer as the Ice Bucket Challenge swept across the U.S. and abroad (see [Sept 2014 news story](#)). The ALSA has responded to the urgency expressed by the ALS research and patient communities, and announced on October 2 an initial commitment of \$21.7 million in funding for six new initiatives to accelerate the development of treatments and a cure for ALS. Together with the \$12.5 million in matching donations, the total commitment reaches \$34.2. Four of these are collaborative research programs were selected as critical for discovering new ALS therapies: ALS Accelerated Therapeutics (ALS ACT), The New York Genome Center, the Neuro Collaborative, and Project MinE (for more about Project MinE see [Apr 2014 news story](#), [Jul 2014 news story](#)). Click [here](#) to read about these exciting new initiatives that would not have been possible without the outpour of support this summer!

[Identical Twins, Only One with ALS](#)

The C9ORF72 gene continues to baffle scientists! Repeat expansions in the C9ORF72 gene are the most common known genetic cause of ALS

October 7-8, 2014: San Francisco, CA: [The 13th Annual BIO Investor Forum](#)

October 7-11, 2014: Berlin, Germany: [19th International World Muscle Society Congress](#)

October 12-14, 2014: Baltimore, MD: [American Neurological Association's 2014 Annual Meeting](#)

October 20-21, 2014: Boston, MA: [AMDIS Fall Symposium](#)

October 22-24, 2014: Clearwater beach, FL: [NEALS Annual Meeting](#)

October 23-25, 2014: Vancouver, Canada: [The 9th International Conference on Frontotemporal Dementias](#)

November 2014

November 7, 2014: Boston, MA: [10th Annual ALS TDI Leadership Summit](#)

November 13-14, 2014: Arlington, VA: [24th Neuropharmacology Conference](#)

November 13-14, 2014: Arlington, VA: [9th Brain Research Conference Neuroprotection: Basic mechanisms and translational potential](#)

November 14, 2014: Washington, DC: [Advances in ALS and FTD Genetics Workshop](#)

November 15-19, 2014: Washington, DC: [The Annual Society for Neuroscience Meeting](#)

November 16-18, 2014: New York, NY: [Partnering for Cures](#)

and frontotemporal dementia, with patients typically carrying hundreds or thousands of repeats as compared to approximately 30 copies in healthy individuals. Now, a remarkable case reported in the September 10 *Neurology* online by researchers led by Ekaterina Rogaeva from the University of Toronto and Lorne Zinman of the Sunnybrook Health Sciences Centre in Toronto, describes identical twins that carry identical C9ORF72 repeat expansions but only one developed ALS. Are environmental influences responsible for this discordance or differential expansions across tissues (see [Jan 2013 news story](#))? Clear [here](#) to find out more about this case and other twin studies in ALS.

[First Mouse Model for ALS-dementia Developed](#)

In 2011, ALS-causing mutations in ubiquilin2 (UBQLN2) were first identified, providing a direct link between the proteasomal degradation pathway and ALS (see [Aug 2011 news story](#)). In a report in the September 22 *Proceedings of the National Academy of Sciences*, the same team, led by Teepu Siddique at the Northwestern University Feinberg School of Medicine in Chicago, Illinois, described a new mouse model carrying these mutations. The model recapitulates behavioral, neurophysiological and pathological changes that are observed in human ALS-dementia. The mouse model will facilitate examination of brain activity in living mice, as well as serve as a new tool to test candidate therapies in ALS and ALS-dementia. Click [here](#) to read more.

[New ALS Registry Reports Prevalence of ALS in the U.S.](#)

The largest epidemiologist survey ever undertaken in the U.S. for ALS reported 12,187 cases as of 2011. The survey, published July 25 in the supplementary edition of *Morbidity and Mortality Weekly Report* by Paul Mehta from the Agency for Toxic Substances and Disease Registry, Atlanta, Georgia and colleagues, is the first publication from the U.S. [National ALS Registry](#). The data is derived from four nationwide administrative databases and a self-reporting web portal that were integrated into a single registry. In addition to serving as a comprehensive and systematic resource on the current state of ALS, the registry could potentially provide a large dataset for environmental risk analysis, if the data use and privacy constraints are resolved. Click [here](#) to read more about this valuable new resource and the potential collaborations surrounding it.

Drug News

[NIH Awards \\$46 Million as Part of the BRAIN Initiative](#)

The Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, launched by President Obama last year, is a large scale effort to advance our understanding of the brain and to develop the technologies necessary to do so (see [NY Times story](#), and [Oct 2013 news story](#) about a project already supported by this initiative). The Initiative is a partnership of the NIH, the FDA, the National Science Foundation (NSF) and the Defense Advanced Research Projects Agency (DARPA), who have jointly committed \$110 million in funding for the 2014 fiscal year. The NIH has just announced its initial round of investments amounting to \$46 million distributed over 58 grants. The funded projects are targeted at developing novel tools for large-scale recording and imaging of brain activity, for analyzing brain cells and

December 2014

December 3-5, 2014: San Antonio, TX: [World Stem Cell Summit](#)

December 3-6, 2014: Cold Spring Harbor, NY: [Neurodegenerative Diseases: Biology & Therapeutics](#)

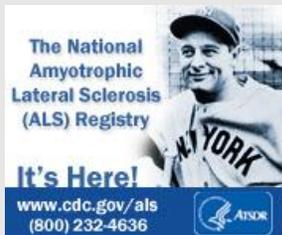
December 5-7, 2014: Brussels, Belgium: [International Conference on ALS/MND](#)

December 17-20, 2014: Hotel Vila Galé Coimbra, Portugal: [Mitochondria, Metabolism and Disease](#)

January 2015

January 13-17, 2015: Hokkaido, Japan: [Society for Neuromuscular Sciences 8th Annual Scientific Meeting](#)

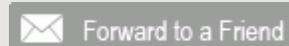
January 25-30, 2015: Taos, New Mexico: [Neuroinflammation in Diseases of the Nervous System](#)



Download your free copy:



Send the ALS Forum e-Newsletters to your colleagues!



circuitry, and for classifying neuronal diversity in the brain. While the support is primarily directed toward basic research, the tools developed through this initiative are expected to substantially accelerate development of novel therapeutics. Read more about it [here](#).

[Patient Advocacy Group Drafts Clinical Trial Guidance for the FDA](#)

For many of the thousands of orphan diseases, not only is there no effective treatment, but there is no existing FDA guidance on the regulatory requirements for obtaining approval for a new one. The [Parent Project Muscular Dystrophy](#) (PPMD) has taken the reins in their hands and submitted the first draft clinical trial guidance document ever submitted to the FDA by a parent advocacy group. The PPMD, which is comprised of parents of children with Duchenne muscular dystrophy (DMD), worked with a wide range of stakeholders, including academics from the U.S. and E.U., industry partners and DMD advocacy groups to draft the document outlining clinical strategies and potential surrogate endpoints for a clinical trial. Hopefully this will encourage other patients groups to follow suit - the ALSA has [today announced](#) such an initiative to develop guidance for ALS. Read this fascinating story of this new milestone in patient advocacy [here](#).

[GlaxoSmithKline Announces \\$5 Million Bioelectronics Fund](#)

Bioelectronic medicine refers to a relatively new field of therapeutics that uses miniaturized, implantable devices to regulate neuronal activity. These devices can potentially treat not only disorders of the nervous system, but also inflammatory processes and muscle activity, making them relevant as potential ALS therapeutics. GlaxoSmithKline (GSK) has demonstrated its growing interest in the field by invested \$50 million in a new venture capital arm to fund bioelectronics technologies, called [Action Potential Venture Capital](#). In addition, they launched a \$1 million Bioelectronics Innovation Challenge last December. They have now announced a \$5 million fund to back academic scientists and companies seeking to solve this challenge. All technologies developed with these funds will be made freely available to the research community. Read more about this exciting, futuristic technology [in the NY Times](#) and [here](#).

[Janssen and U of T Partner to Tackle Neurological Diseases](#)

The University of Toronto (U of T) has announced a new collaboration with Janssen Inc. to develop therapies for neurological diseases, including mood disorders and neurodegenerative diseases. The collaborative project, called *Neuroscience Catalyst*, was facilitated by [Johnson and Johnson Innovation Center](#) in California, and will help identify and support promising early stage discoveries that can be advanced into the clinic. U of T is co-funding the project, and is forming a joint steering committee with Janssen that will oversee the partnership and select the proposals for award. The research teams will benefit from funding, as well as access to drug development tools and expertise from Janssen. Click [here](#) to read more about this new university-industry partnership.

The ALS Forum was developed by [Prize4Life, Inc.](#)

Identified content provided through a partnership with [Alzforum](#).

[Forward email](#)

This email was sent by contact@prize4life.org |
[Update Profile/Email Address](#) | Rapid removal with [SafeUnsubscribe™](#) | [Privacy Policy](#).



Prize4Life, Inc. | PO Box 5755 | Berkeley | CA | 94705