



We hope you all had an amazing July 4th weekend. We skipped a week, but are back in full steam. 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:

Visit the new ALSGene tool at www.ALSGene.org

Visit the PRO-ACT Database at www.ALSDatabase.org

[NEALS Biofluid Repository Available to Researchers](#)

[NINDS Fibroblast Repository](#)

[VABBB Tissue Request Information Site](#)

Funding Opportunities:

[The Association for Frontotemporal Degeneration RFPs](#)

[Blueprint Neurotherapeutics Network \(BPN\): SBIR Small Molecule Drug Discovery and Development for Disorders of the Nervous System \(U44\)](#)

[Bernice Ramsay Innovation Grants: 2014 Discovery Grant](#)

Webinars:

July 16, 2014, 2-3pm EST: [ALSA/NEALS PALS "Stem Cells Webinar"](#)

Research News

[Rebuilt Version of ALSGene Database Ready for Prime Time](#)

An updated and improved version of the [ALSGene](#) database is now available! The ALSGene database is a public database of genetic-association studies in ALS that contains data on thousands of genetic polymorphisms from genome-wide association studies (GWAS). Lars Bertram and colleagues from the Max Planck Institute for Molecular Genetics in Berlin have curated published genetic data and added in capabilities for meta-analysis, and [Prize4Life](#) has provided the majority of funding for building and maintaining the database. ALSGene currently contains data from 297 genetic studies spanning nearly 240,000 polymorphisms. Systematic access to these datasets will be useful to investigators trying to identify genetic causes of sporadic forms of ALS, as well as genetic variants that modify disease. It will also hopefully encourage basic researchers to investigate the functions of important ALS genes identified through ALSGene. Click [here](#) to read more about this great resource!

[Mitochondrial Mutation Linked to Atypical ALS-FTD](#)

Malfunctioning mitochondria, the essential energy-producing cellular organelles, have been implicated in ALS as well as in other neurodegenerative diseases (see [Jan 2012 News](#), [Feb 2010 News](#)). A new study published in *Brain* online on June 16 by Véronique Paquis-Flucklinger and colleagues at Université de Nice Sophia Antipolis in Nice, France provides the first genetic link between families believed to have ALS with frontotemporal dementia (ALS-FTD) and a mitochondrial mutation. The researchers identified two families with multi-system disorders that include motor neuron degeneration who also carry a mutation in a gene coding for a mitochondrial protein. Mutations in this gene, called CHCHD10, or repetitive moniker coiled-coil-helix-coiled-coil-helix domain containing 10, lead to disorganized and fragmented mitochondria with cristae that do not form properly. Although the ALS-FTD diagnosis of these families is disputed among experts, this paper provides important insight into how mitochondrial dysfunction detrimentally affects motor neurons, and expands the spectrum of multi-system diseases caused by mutations in mitochondrial proteins (see [Mar](#)

Upcoming Meetings:

July 12-17, 2014:
Copenhagen,
Denmark: [Alzheimer's Association International Conference](#)

July 13-15, 2014: Prince Edward Island,
Canada: [Biotechnology & Human Health Symposium](#)

July 27 - August 1, 2014:
Girona - Costa Brava,
Spain: [Gordon Research Conference: Neurobiology of Brain Disorders, Neurodegeneration and Aging-related Disorders of the Nervous System](#)

August 2014

August 3-8, 2014: Andover, NH: [Gordon Research Conference: Musculoskeletal Biology & Bioengineering, Identifying and Overcoming Barriers to Translation](#)

August 3-8, 2014:
Waterville Valley,
NH: [Gordon Research Conference: Synaptic Transmission, Synapses in Networks](#)

August 10-15, 2014:
Newport, RI: [Gordon Research Conference: Neural Development, From Stem Cells to Circuits](#)

September 2014

September 8-10, 2014:
Philadelphia, PA: [3rd International Conference and Exhibition on Neurology & Therapeutics](#)

September 17-20, 2014:
Minneapolis, MN: [1st ALS Research Group Meeting](#)

October 2014

[2013 News](#)). Click [here](#) to read more.

[UK 'Whole Genome Sequencing Project' to Sequence 1,500 ALS Genomes](#)

The UK Whole Genome Sequencing Project is an exciting new initiative to sequence 1500 genomes from ALS patients just announced by the UK Motor Neurone Disease (MND) Association. The goal of the project is to identify previously unknown, rare genetic variants that contribute to the sporadic forms of the disease. The project will use DNA samples already collected and stored in the UK MND DNA bank from sporadic ALS patients. This UK program is part of a larger international collaboration with Project MinE (see [Apr 2014 News](#)), and has already engaged some of the leading ALS researchers in the UK. Over the next few years, we hope to see an increasing number of countries joining this international initiative. Click [here](#) to read more about this initiative.

[Astrocytes Help Neurons With Mitochondrial Waste Disposal](#)

The established paradigm in biology is that healthy cells dispose of their own damaged mitochondria via an autophagy-like process called mitophagy. However, a recent study published July 1 in the *Proceedings of the National Academy of Sciences* and led by Nicholas Marsh-Armstrong's groups at Johns Hopkins University and Mark Ellisman's group at University of California, San Diego, challenges this assumption. The researchers elegantly demonstrate that in the optic nerve head, astrocytes take up mitochondria from axons of neighboring retinal ganglion cells and degrade them. Is this phenomenon more widespread in the brain? This is still unknown, but waste buildup in neurons contributes to neuronal death in ALS and other neurodegenerative diseases, so it will be of utmost interest to explore whether similar processes occur in other neuron types and how they contribute to disease. Click [here](#) to read more.

Drug News

[Kadimastem's Stem Cell Therapy Holds Promise For Treating ALS](#)

The Israeli biotechnology company [Kadimastem](#) has announced exciting results from their first preclinical study in ALS. The company's proprietary technology is based on stem cell-derived astrocyte precursor cells, which are transplanted into the cerebrospinal fluid (CSF) to provide support for degenerating motor neurons. The technology was initially developed out of the laboratory of Professor Michel Revel, Kadimastem's Chief Scientist and also the lead inventor of the blockbuster multiple sclerosis drug Rebif®. Kadimastem's preclinical study in ALS demonstrated that the transplanted cells increase survival and motor function in an ALS mouse model. Next steps are to engage the FDA and other regulatory authorities in discussions in preparation for a human clinical trial. Keep your finger on the pulse of this company! Click [here](#) to read more.

[Q-Therapeutics Obtains First U.S. Patent for Astrocyte Family of Neural Cells](#)

Another emerging biotechnology company to keep an eye on in the ALS stem cell therapy arena is Salt Lake City, Utah-based Q-Therapeutics.

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

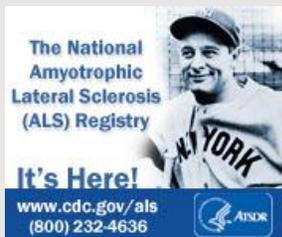
October 23-25, 2014:
Vancouver, Canada: [The 9th International Conference on Frontotemporal Dementias](#)

November 2014

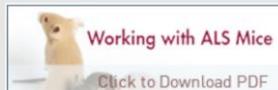
November 13-14, 2014:
Arlington, VA: [24th Neuropharmacology Conference](#)

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

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



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The company has just been granted its first U.S. patent in its fifth family of patents on neural cells, which covers the astrocyte family of neural cells of the central nervous system (CNS). The company's transplanted stem cell-derived astrocytes can provide both trophic support and reduce inflammation, and in addition have the capacity to provide long lasting treatment effects. Since defective astrocytes are implicated in many neurodegenerative diseases, these cells have potential for a wide range of indications. The lead inventor on the patents is Dr. Mahendra Rao, who is also the scientific founder and Chief Strategy Officer of Q-Therapeutics. The company is first aiming to treat ALS and expects to submit its first investigational new drug (IND) in 2014 (see [Apr 2014 News](#)). Click [here](#) to read more.

[Patient Combines Crowdsourcing and Drug Testing to Find an ALS Therapy](#)

People with ALS (PALS) are leading some of the most innovative efforts to accelerate therapy development for ALS. Recently, we reported on the PALS-led investment fund for ALS (see [April 2014 News](#)). Another inspiring example is the SciOpen Research Group (SRG), a non-profit biotechnology company co-founded by the PALS Eric Valor, a patient activist who is also on the board of directors of the ALS Emergency Treatment Fund (see [Feb 2013 News](#)). The SRG has recently completed a \$30,000 crowdsourcing [campaign on IndieGoGo](#) to fund an ALS drug testing project at the Salk Institute. The company also has its eyes on epigenetics and stem cell research for ALS. To read more about the SRG, click [here](#).

[PatientsLikeMe and CATCH Collaborate to Improve Patient Care](#)

The online patient-centered network [PatientsLikeMe](#) (see [Apr 2014 News](#)) has entered into a collaboration with the [Center for Assessment Technology and Continuous Health](#) (CATCH) at Massachusetts General Hospital (MGH) and Massachusetts Institute of Technology (MIT). CATCH is a multidisciplinary patient-focused center that is developing quantitative tools aimed at integrating a variety of genotype and phenotype data with clinical outcomes to improving monitoring and treatment of disease. The goal of this partnership is to integrate PatientsLikeMe's virtual registry data into research initiatives at CATCH help validate analytical approaches that can help bring solutions to patients across many diseases, including ALS. Click [here](#) to read more.

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