

## **ABC UPDATE 11/1/2016**

President Obama hosted a White House Frontiers Conference in Pittsburgh. The President highlighted the progress that his Administration has made on his inaugural pledge to "restore science to its rightful place," but also focused on the future and what can be made possible through science and technology. Be sue to check out the President's remarks and panel discussion on the future of health and medical research here.

The U.S elections are rapidly approaching, and science funding will be a topic that needs much attention. Science Magazine <u>released advice</u> regarding science funding for the next President of the United States.

BIO is pleased to announce its fifth annual <u>Patient and Health Advocacy Summit</u> to be held soon in Washington, DC. This event brings together patient advocacy organizations, academia, regulators, biotechnology industry, and other stakeholders for two days of robust programming to discuss timely policy issues and share best practices.

## The American Brain Coalition is pleased to welcome three new Non-profit members to our membership list:

The <u>Patrick Risha CTE Awareness Foundation</u> is a Pennsylvania non-profit volunteer based organization. It was created in Patrick's memory to help prevent CTE in future athletes and provide a resource for understanding the disease, how it is caused, and its relevance in youth sports.

The Mission of <u>The Brain Donor Project</u> is to advance science leading to the treatment and cure of neurological, neuropsychiatric and neurodevelopmental disorders, by increasing awareness and simplifying the process of donating post-mortem human brains for research. Please see the attached two-page piece that serves as a quick introduction to this project, and feel free to share it with your members.

The Coffin-Lowry Syndrome Foundation was created in 1991 when my then infant son, Davis, was diagnosed with the condition. I searched for information and found very little was available. I contacted the National Organization of Rare Disorders (NORD), assuming that maybe they would have a dozen or so families in the U.S. in their database. At that time, there was only one other family in the NORD database - they had a 22 year-old daughter. Communicating among ourselves, we eventually expanded this to a half-dozen families. We all said the same thing, it's too bad there isn't a support group. Someone should start one. Well, I thought, I'm someone. Maybe I should start a support group. And CLSF was born. CLSF has been a great resource for families affected by CLS. It gives us a place to share much-needed information that just doesn't exist anywhere else. We have been instrumental in working with the research group in France that eventually identified the RSK-2 defect that causes CLS. It is by sharing what we know with each other that helps all of us more effectively help our children live the best life they can live.

## IN THE NEWS

- The Brain & Behavior Research Foundation announced the winners of the 2016 Pardes Humanitarian Prize in Mental Health. You can read more about the outstanding awardees <a href="here">here</a>.
- Check out the <u>Capitol Hill Report</u> from the American Academy of Neurology (<u>AAN</u>) that talks about the the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) Rule.
- The National Institute on Alcohol Abuse and Alcoholism (NIAAA) announced that Michael E. Charness, M.D., will deliver the 21st Annual Mark Keller Honorary Lecture. Dr. Charness is an internationally recognized neurologist whose work has greatly advanced our understanding of how alcohol affects the development of the nervous system.





- NIH-funded scientists propose using an assessment tool to diagnose addictive disorders that considers
  addiction-related behaviors, brain imaging, and genetic data. This would facilitate future understanding of the
  origin of addiction at a biological level, and could ultimately lead to more effective individualized treatments for
  addictions.
- Read about the <u>Smartphone Study</u> the purpose of which is to figure out whether smart phones can be used to track symptoms of depression or mania. Another interesting study is the <u>Student Mental Health Research Study</u> in which researchers are trying to learn more about how we can support students with mental health issues to help them succeed in school. Other new studies are the <u>Tardive Dyskinesia Study</u> and the UCSD Bipolar Disorder Brain Research Study. For the last study, you can contact Nana Kori at 858-534-9439 or at <a href="mailto:nkori@ucsd.edu">nkori@ucsd.edu</a>.
- <u>IMHRO</u> recently announced that it will be known simply as One Mind Institute. This organization will continue its efforts of funding brain science to improve lives.
- In new science news.
  - Researchers identify a gene associated with post-traumatic stress disorder
  - Shyness in early childhood can afect how the preteen brain becomes wired for social interaction
  - A study done in mice suggests that <u>bone loss may be a side effect of some</u> antidepressants
  - o A breakthrough in the effort to develop a fast-acting antidepressant

## FOR AMERICAN BRAIN COALITION MEMBERS

- The Annual meeting of the American Academy of Addiction Psychiatry (<u>AAAP</u>) will be held at Bonita Springs, Florida in December, 2016! Check out the Preview Guide <u>here!</u>
- AAAP's Premier Course is still open for registration! <u>Here</u> is the information for this course which is for anyone interested in learning more about substance use disorders and to help prepare for subspecialty certification and maintenance of certification.
- Watch a <u>webinar</u> released by the International Bipolar Foundation exploring the controversy of using cannabis therapeutically for mood stabilization, anxiety reduction, and the promotion of sleep.
- Movement 2017 will be held at Oxford University in July 2017. The purpose of the conference is to share knowledge of all whose interests lie in the nature of human movement. We hope you will consider attending!
- The National Association for Biomedical Research (<u>NABR</u>) needs our help! NABR's next exclusive webinar, <u>Help Us Help You: Participating in the Public Policy Process</u>, will provide participants with the necessary information to become an active participant in the regulatory and legislative processes and provide guidance about how to help shape the environment in which NABR members work.
- The American Association for Laboratory Animal Science (<u>AALAS</u>) meeting is going on as we speak! Matt Bailey
  and Taylor Bennett from <u>NABR</u> are all set to present their work on welfare for animals in research.
- The American Society for Experimental Therapeutics (<u>ASENT</u>) is pleased to announce its 2017 Annual Meeting with very special programs designed specifically for its membership and welcome new attendees. A new exciting course is the <u>Clinical Translation Course</u>.
- Register for a conference entitled "Health Systems and Addiction: The Use and Misuse of Legal Substances" to be held on Nov 16, 17, 2016.
- Schizophrenia and Related Disorders Alliance of America (SARDAA) has launched "Hearing Voices of Support". See how you can get involved in the attached press release.
- The Annual Meeting of the American Society of Clinical Psychopharmacology (<u>ASCP</u>) will be held at the Loews Miami Beach in summer of 2017. Submissions for the meeting are now open!
- The 2016 Nike Mag recently raised \$6.75M in support of Parkinson's Research. You can read more about this endeavor here.
- Register for a webinar entitled "Could We Someday Prevent Schizophrenia Like We Prevent Cleft Palate?" to be held in November 2016.