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FROM THE CEO'S DESK

With an ever-stronger base of basic research, growing assets like our SolveCFS BioBank and new scientific and computational tools added to the research arsenal, the CFIDS Association is prepared to seize new opportunities and engage more broadly. Recent recognition by the FDA creates new opportunities to attract partners and fast-track promising therapies. Together, we are on the leading edge of change. [Together, we can create a world free of CFS.](#)



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NEW @ RESEARCH1st

Upcoming Ampligen

Review: On December 20, the FDA's Arthritis Advisory Committee will meet in

open session to review the application from Hemisphere Biopharma to market its experimental immunomodulatory drug rintatolimod (Ampligen) as the first treatment for CFS. The meeting will be webcast live. The agency is expected to render a decision by February 2, 2013. For further background information and links to media articles about the pending decision, please see <http://bit.ly/FDA-Ampligen-review-set>.

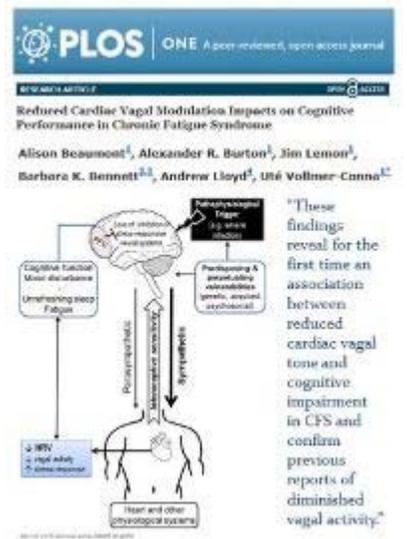


Meeting of the FDA's Arthritis Advisory Committee to review data on rintatolimod (Ampligen) in the treatment of CFS



Top Prize in Sanofi's Collaborate | Activate Challenge: We're thrilled to share the announcement from Sanofi US that *Registries for All Diseases* has been selected as the winner of the [Collaborate Activate Innovation Challenge](#). *Registries for All Diseases* received a \$300,000 award to create a comprehensive, crowdsourced, cross-disease registry to help accelerate translational research for over 1,000 diseases. The team consists of partnering organizations Genetic Alliance, **CFIDS Association of America**, National Psoriasis Foundation, and the Inflammatory Breast Cancer Research Foundation. Read more about the project and contest at <http://bit.ly/top-prize-c-a>.

Cardiac Rate and Cognition Linked: Researchers at the University of New South Wales studied 30 CFS patients and 40 healthy controls with EKG, perceived fatigue/effort and cognitive performance during mental tasks. They report: "Patients with CFS showed no deficits in performance accuracy, but were significantly slower than healthy controls. CFS was further characterized by low and unresponsive heart rate variability; greater heart rate reactivity and prolonged heart rate-recovery after cognitive challenge." ([PLOS ONE](#); Nov. 14, 2012)



EBV Subset Identified: Drs. Martin Lerner and Ron Glaser used a specialized testing panel for Epstein-Barr virus (EBV) antibodies to differentiate six CFS patients from 20 healthy controls. The CFS patients were treated with valgancyclovir for at least 12 months and all improved based on questionnaire data collected before, during and after treatment. ([PLOS ONE](#); Nov. 14, 2012)

Immune Differences Between GWS & CFS: A team led by Drs. Gordon Broderick and Nancy Klimas showed immune system differences between CFS patients (n=7) and Gulf War syndrome patients (n=20) in spite of clinical features shared by the two conditions. The CFIDS Association helped support these investigators. ([Brain, Behavior & Immunity](#), Nov. 29, 2012)

Easier Way to Detect POTS? Dr. Julia Newton's group in the U.K. reported a subtype of CFS with postural orthostatic tachycardia syndrome (POTS), representing 13% of a selected cohort seen at her clinic. While this finding is not new, their ability to detect the subtype using only paper instruments instead of the expensive and relapse-provoking tilt test may be an important clinical advance to help guide diagnosis and management. ([Journal of Internal Medicine](#), Dec. 4, 2012)

Flu Shot or Not? A small pilot study of 7 CFS patients meeting Fukuda criteria reaches no firm conclusions about the relative risk/benefit of annual flu vaccinations. Although researchers at the Bond University in Australia found a degree of immune dysregulation following vaccination, results were not consistent. ([International Journal of Clinical Medicine](#), Nov. 2012) People with CFS should make the decision about the flu shot with their health care team and use past experience as a guide. Keep in mind the risks flu poses to others in your household as well as yourself.

Review all the journal highlights at Research1st: <http://bit.ly/journal-hilites>

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NEWS & EVENTS

Nov. 29, 2012: The Association presented its partnership with Biovista to repurpose existing drugs for CFS at the **Partnering for Cures** conference hosted by *FasterCures*. Thirty organizations were selected by *FasterCures* for these sought-after "[Innovator presentations](#)" to feature collaborations that cut the time to get cures to people who need them. You can watch the session here: <http://www.partneringforcures.org/2012/p4cprogram.taf?function=detail&EvID=4172&eventid=p4c11>



Dec. 20, 2012: The Arthritis Advisory Committee will review the New Drug Application submitted by Hemispherx Biopharma to market its drug, Ampligen, to treat CFS. The meeting will be webcast list. More details: <http://1.usa.gov/SVpfho>

Jan. 14, 2013: The CDC will host a Patient-Centered Outreach and Communications Activity teleconference at 3:00 PM (EST). The topic of this meeting will be "redefining exercise in CFS through redefining aerobic activity" and the guest speaker will be Dr. Nancy Klimas. CDC staff will also provide updates on their research and outreach programs. To be added to the mailing list for further details, please send an email message to: CFSPCOCACall@cdc.gov

Next spring, FDA will sponsor a stakeholder meeting about development of safe and effective drugs for ME and CFS. We'll share additional details as they become available. The FDA has archived

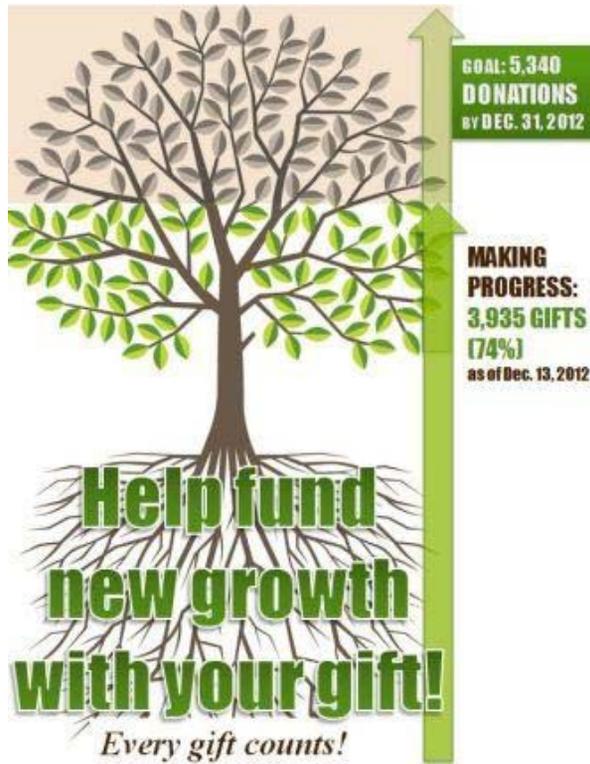
information about drug development in ME/CFS here: <http://1.usa.gov/Nlzk2S>

Medscape, one of the world's top online resources for health care professionals, has partnered with CDC to provide info about CFS and its educational impact in an article and resources, including several from the CFIDS Association/Research1st. Please share this link: <http://bit.ly/back-to-school-CFS>.



Missing our updates in your Facebook news feed? Changes to Facebook require that you "subscribe" to page updates in order to see them in your news feed. It takes just a minute to [visit our page](#) and click "subscribe." We hope you will and that you'll take part in the discussion, too!

Your [year-end contribution](#), leveraged by thousands of others made by like-minded people to the Association, will **change the way that CFS research is conducted** -- breaking down silos and connecting talented investigators through our [Research Institute Without Walls](#). Please make a gift today to help change the future for people living with CFS. Every gift -- small or large -- matters. We are approaching the "tipping point" for real, meaningful progress. [Every gift](#) moves us closer. With your help, we will make CFS history. Thank you!



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The CFIDS Association of America

Our Mission:

For CFS to be widely understood, diagnosable, curable and preventable.

Our Strategy:

To stimulate research aimed at the early detection, objective diagnosis and effective treatment of CFS through expanded public, private and commercial investment.

Our Core Values:

To lead with integrity, innovation and purpose.

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