Research1st News from the CFIDS Association of America
September 17, 2012 | Vol. 1, No. 15

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NEW @ RESEARCH1st
Results of the long-anticipated study of XMRV and pMLVs in CFS coordinated by Dr. Ian Lipkin will be published Tuesday, Sept. 18, 2012 at 12:01 a.m. in the online open access journal mBio. Five of the study authors will address the public at 10:30 a.m. in a press conference being webcast from Columbia University. Details here on Research1st: http://bit.ly/XMRV-results-coming-soon

The CFIDS Association of America is partnering on two proposals for patient-centered research selected as finalists in Sanofi’s Collaborate | Activate Innovation Challenge, as Sanofi announced today. We advance to compete for a top prize of $300,000 and second prize of $100,000 with help from Sanofi in the form of $25,000 and a planning mentor they provide to each team. Learn more about the Challenge and the finalists’ proposals: http://bit.ly/sanofi-challenge

Representatives from the Food & Drug Administration held a teleconference with ME/CFS stakeholders on Sept. 13. During they call they reiterated that FDA considers ME/CFS to be a "serious and life-threatening condition," making applications to study ME/CFS treatments eligible for

COMING SOON:
XMRF/pMLV STUDY RESULTS

THE CENTER FOR INFECTIOUS DISEASES

TWiV

SANOFI PARTNERS IN PATIENT HEALTH INNOVATION CHALLENGE

Sanofi

FINALISTS!

RESEARCH1ST BLOG
expedited review and accelerated approval programs. FDA will convene stakeholders for a scientific meeting this coming spring on clinical endpoints for assessing the effectiveness of treatments in clinical studies. Here's a brief summary from Research1st:

Single lab studies are finding it hard to compete in the tighter race for federal grant funds. Former NIH program officer Dr. Dennis Mangan outlines how "team science" can be applied to understand complex conditions like CFS: http://bit.ly/team-science

JOURNAL HIGHLIGHTS @ RESEARCH1st

Post-Infection Cytokine Signature: Gordon Broderick et al., compared multiple immune system measurements over time in a group of girls who recovered from infectious mono (EBV infection) to a group who didn't recover and met criteria for CFS at 24 months. They report, "differences were especially evident when cast in the context of [immune system chemicals] IL-1a, IL-2 and IFN-y. This evidence points to a possible dysregulation of the innate system's priming of the appropriate adaptive Th17 response in these subjects." The authors, including CFIDS Association scientific director Dr. Suzanne Vernon, suggest that this profile offers a possible diagnostic test for post-infectious CFS with more study. (Journal of Translational Medicine, Sept. 13, 2012) This study was funded by the CFIDS Association of America. More info: http://www.research1st.com/2011/11/30/broderick-2/

Mitochondrial Exhaustion: In this review, Gerwyn Morris and Michael Maes suggest that an interplay between intracellular molecules such as NF-kB and p53 and mitochondrial dysfunctions are the underlying basis for exhaustion, neurocognitive dysfunction and post-exertional relapse in ME/CFS. They suggest that future research should examine p53 signaling in ME/CFS. (Medical Hypotheses, Aug. 29, 2012)

Review all the journal highlights recently updated at Research1st: http://bit.ly/journal-hilites
POLICY MATTERS

The federal CFS Advisory Committee meets next in Washington, D.C. on Oct. 3-4, 2012. Registration to attend in person (deadline Sept. 28) and/or to offer public testimony (in person or by phone; deadline Sept. 24) is now open at http://www.blsmeetings.net/CFSACOctober2012/ The agenda has not yet been posted.

CATALYSTS IN ACTION

Mark Williams became ill during his collegiate naval training more than 20 years ago. Now his wife, Jennifer, is channeling the strength and determination she's watched him demonstrate every day since she trains for her first marathon. Their enthusiastic outreach has already generated more than $2,808 for the cause, exceeding their $2,620 goal! Read more about the Williams in this Catalyst profile. Cheers to Jen and Mark for raising awareness and funds!

Following up on a promise President Obama made to Courtney Miller at a town hall meeting in April 2011, the couple received personal contact and a written letter from the White House, along with a commitment from the president to elevate the priority CFS receives from the National Institutes of Health. Courtney and husband, Robert, who has had CFS for more than two decades, pledge to apply the same persistence to getting that promise fulfilled as they did to the original one. Read more in "White House Responds to ME/CFS Advocate."

Our fifth and sixth donor events of the year will be held in Manhattan on Sept. 29 and Washington, D.C. on Nov. 4. These events provide an opportunity to connect with Association leaders and other guests, share insights and ask questions. We're mobilizing support for patient-centered research conducted through our Research Institute Without Walls and reporting to you on the return on your investment. For more details, please send a message to Gloria Smith at gesmith@cfids.org; please indicate which location you're interested in.

Donors to the Catalyst Fund receive monthly updates from Association leaders and news about the people who fuel the Association's research-focused mission. They also receive advance invitations to special events around the country and on the web. Make a gift today in support of research and stay in the know!

OTHER NEWS & UPCOMING EVENTS

Genetic Alliance is conducting a short, anonymous survey about biobanks. (We are defining biobank as a collection of human biological samples, such as blood

Whether you currently participate in one or more biobanks or you've just thought about it, we value your insights and opinions.
or tissue samples and the information associated with these samples, such as health information, that are stored for future use and managed according to professional standards.) We are asking current biobank participants and those who may be interested in participating in biobanking in the future to help take the community's "pulse" on biobanking. This survey has been approved by the Genetic Alliance Institutional Review Board #IORG0003358. [Take the survey]

**Hyperion Biotechnology** won a "distinguished abstract" award at the 2012 Conference of the American Association of Clinical Chemistry for its research on a salivary biomarker to diagnose CFS. Hyperion has been collaborating with CDC to identify a non-invasive test to help diagnose CFS. Press release: [http://bit.ly/U7Tzry](http://bit.ly/U7Tzry)

**Sept. 29**: Join us in **Manhattan** for a **Catalyst Café event**, an opportunity to hear from our CEO, Kim McCleary, and Scientific Director, Dr. Suzanne Vernon, about the Association's "**Research Institute Without Walls**" research program and progress in the field. Special guest **Dr. Dikoma Shungu** of Weill Cornell University will also share an update on his research. Please send an email to Gloria Smith at [gesmith@cfids.org](mailto:gesmith@cfids.org) for more information.

**Oct. 3-4**: The federal **CFS Advisory Committee** meets in Washington, D.C. For further details: [http://www.hhs.gov/advcomcfs/index.html](http://www.hhs.gov/advcomcfs/index.html)


**Nov. 4**: We'll host a **Catalyst Café event** in **Washington, D.C.** Details are still being finalized; if you'd like to receive more details, please send an email to Gloria Smith at [gesmith@cfids.org](mailto:gesmith@cfids.org).

We regularly update the year's **newsworthy highlights** on Research1st. Catch up on the latest between monthly emails: [http://bit.ly/news-2012](http://bit.ly/news-2012) Our [Facebook page](http://www.facebook.com) is another excellent source of daily updates. You can view the page as often as you like, even without a Facebook account.

**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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