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Research **1st** News from the CFIDS Association of America January 2012 | Vol. 1, No. 1

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A NEW LOOK!

The CFIDS Association has put research first to end the lifealtering disability, stigma and isolation of CFS. Our Research1st website and blog is your home on the Internet for current, reliable information about CFS research. We've given our monthly e-newsletter a new look and a new name to streamline the information resources we provide to the community. This month, CFIDSLink becomes Research1st News. Until the transition is complete, the email address used to send our newsletter will remain cfidslink@cfids.org.



FROM THE CEO'S DESK

This fall, you helped us respond to five different challenges and one "bonus" issued by donors to help inspire year-end giving. We are grateful to everyone who responded and helped us secure a total of \$1,217,177 in support of The Catalyst Fund. Read more...



THANK YOU!



NEW @ RESEARCH1st

LOOKING FORWARD: RESEARCH INITIATIVES IN 2012: We've recapped what to look forward to in 2012 from research initiatives announced in 2011. Read more....



PAIR OF RETRACTIONS ISSUED: On Dec. 23, Science editor-in-chief

Bruce Alberts <u>issued a rare editorial retraction</u> of the 2009 paper by Lombardi et al. that first linked CFS to XMRV. On Monday, Dec. 26, the authors of the only other published paper supporting this association retracted their study from the *Proceedings of the National Academy of Sciences*.

XMRV attracted a lot of media attention in 2011, but **other newsworthy stories** raised awareness too. Read more...

We added 15 new posts since Dec. 1, with **164 posts** since our Research**1st** blog launched in late May. You can subscribe to email updates each time a new blog post is added.

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JOURNAL HIGHLIGHTS @ RESEARCH1st

Following are selected **highlights from the published literature** in Dec. 2011. Read more...

MARKERS DIFFERENTIATE CFS FROM MS: A new study from the Light team at Univ. of Utah shows unique post-exercise markers in CFS compared to patients with MS and healthy controls. This study was funded in part by the CFIDS Assn. (*Psychosomatic Medicine*, Dec. 30, 2011)



Alan Light, PhD and Kathy Light, PhD University of Utah

NO XMRV IN SPANISH PATIENT COHORT: From Arredondo et al. in Spain, a report of testing for XMRV in 1103 samples collected from

people with CFS, FM, prostate cancer, HIV, HTLV, hepatitis B, hepatitis C, autoimmune disease and healthy blood donors. There was no evidence for XMRV in this cohort. (*AIDS Research and Human Retroviruses*, Dec. 29, 2011)

NO MLV-RELATED VIRUSES IN 8 VACCINES: Researchers at the CDC, Blood Systems Research Institute and Univ. of Cal. at San Francisco report the results of their PCR and deep sequencing tests of 8 live vaccines for MLVs. All were negative for XMRV and MLVs. This is the second published report finding no presence of these viruses in vaccines. (*PLoS ONE*, Dec. 22, 2011)

MODERATE EXERCISE BETTER CHALLENGE FOR DETECTING CFS: A new study published by Dane Cook, PhD, and colleagues at UW-Madison, shows that sustained submaximal exercise challenge demonstrates differences between CFS, CFS+FM and healthy controls better than a short-duration

₾ COLUMBIA UNIVERSITY

OTHER RESEARCH NEWS

Dr. W. Ian Lipkin of Columbia University's Center for Infection and Immunity posted a message on Dec. 28 about the multicenter study he is coordinating for the NIH to address the question of whether a retrovirus is associated with CFS/ME. Read more...

Margaret Anderson, executive director of Faster Cures, spotlights the top 10 medical research trends to watch in 2012 in this Huffington Post article. Read more... Check out our slideshow, "Transforming Research," and you'll see the CFIDS Association is leading these trends! View now...

The **New England Journal of Medicine** turns 200 this year. They've posted an interactive timeline of medical discoveries, 1812-2012. Check it out...

An article from **Genome Web** (free registration) provides a good summary of studies that have found some lab materials to be contaminated with mouse DNA, leading to the possibility of false positive results in viral testing. Read more...

The fall 2011 issue of the IACFS/ME's Bulletin includes an article by **Tom Kindlon** of the Irish ME/CFS Association reporting the harms associated with CBT/GET and the book of abstracts from the IACFS/ME conference held in Ottawa in Sept. Read more...

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POLICY MATTERS

The CFIDS Association is a member of the Alliance for Taxpayer Access that supports barrier-free access to publicly funded research. The **Research Works Act**, introduced in Congress on Dec. 16, 2011, threatens open access and the NIH public access policy. This Wired article explains the legislation and scientists' reaction to it. <u>Read more...</u> PLoS founder Michael Eisen published an op-ed in the NY Times about this pending legislation. <u>Read more...</u>



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CATALYSTS IN ACTION

We have been honored to share stories about our **Catalysts**, supporters of <u>The Catalyst Fund</u>. In science, catalysts are substances that change the rate of chemical reactions. "Positive" catalysts speed a particular reaction. For the CFIDS Association, Catalysts speed transformation through their support of our research program. Meet two more of our Catalysts, both of whom join the Association's Board of Directors this year:

 Beth Garfield, J.D., got sick in 1985 while on vacation. It took four years to get a diagnosis of



CFS, but she also found a treatment that offered relief for 22 years. A relapse this February gave her reason to get involved again. "Even for people who do well for years, CFS is always there - and there's always the possibility of a relapse," she says. "We can either give in to it and live our lives with CFS, or we can fight to find a cure. For me, the choice is clear." Meet Beth...

• Christine Williams, M.Ed., got sick in August 2008, "I just woke up one morning with a terrible, flu-like illness - fever, chills, sore throat, swollen glands. It was the middle of the summer and I just assumed I'd get well but I never felt good again." She appreciates what she calls the organization's "pragmatic" approach to narrowing the focus to research, viewing it as a way to move the research forward and to educate and link the medical community to CFS. Meet Christine...

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OTHER NEWS

We are so fortunate that **Laura Hillenbrand** openly shares her struggle with CFS in interviews like this one published Dec. 21, 2011 in "The Daily Beast." Thank you, Laura! Read more...

294 individuals made donations eligible for entry in the "20/20 Bonus" offered by Laura Hillenbrand to spur year-end giving to the CFIDS Association. We have drawn the winners of 20 rare signed copies of *Unbroken* and are contacting them now to get permission to include their names in the announcement. Stay tuned for that news!



17-year-old **Elodie Lafosse** will carry the Olympic torch. Elodie has CFS and won a writing competition sponsored by Coca-Cola to earn the honor. Read more...

"This Week in Virology," one of the top science podcasts on iTunes, has covered CFS and XMRV numerous times over the past two years. The XMRV story led episodes 164 and 165. Host Dr. Vincent Racaniello is a member of the Association's Scientific Advisory Board. Check out TWIV...



Llewellyn King, host of the PBS program, "The White House Chronicle," started the year with a blog post on Salon about CFS, "In 2012 without care and cure." Mr. King has also produced several short videos about CFS, posted to the MECFS Alert channel on YouTube.

We're grateful for the support of all the individuals, families and organizations who made year-end donations to the Association. Our work is off to a brisk start in 2012 and we need your support year-round to continue the momentum. Why not make the CFIDS Association your first charitable donation of 2012? Our <u>secure online donation site</u> is ready 24/7. 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.



Forward to a friend



