

The more things change, the more they stay the same

Although 13 years have passed since Drs. Barksy and Borus, with the Brigham & Women's Hospital in Boston, MA had published their article, "Functional somatic syndromes" (Ann Intern Med. 1999 Jun 1;130(11):910-21), many patients are still viewed as having "mystery symptoms" without identifiable medical cause.

"Despite a number of high-tech medical tests, many symptoms — such as fatigue and various pains — are never explained. Some doctors are turning to psychological therapies to help patients ignore them."

This is an excerpt of a story released on February 24, 2014, by the Wall Street Journal written by Andrea Petersen, "[Mystery Medical Symptoms Hit a Surprising Number of Patients](#) ." ***This page is still open for comments.***

And, as an antidote...

[Laughter is the Best Medicine](#) (HELPGUIDE.org)

Laughter helps to trigger healthy physical changes in the body, boosts immune system, and helps to promote a more balanced perspective.

This article encourages everyone to find ways to incorporate more laughter into their lives and discusses the many benefits of laughter.

Do you find ways to laugh every day?

ME/CFS Research Updates

[Interview: Ian Lipkin's Million Dollar Appeal for Microbiome Study](#) (Phoenix Rising ME/Chronic Fatigue Syndrome Forums)

On February 10, 2014, Simon McGrath, a writer for Phoenix Rising, conducted an interview with Dr. Ian Lipkin, world-famous scientist and virus hunter. Dr. Lipkin also served as lead researcher of the Chronic Fatigue Initiative (CFI) Pathogen Discovery and Pathogenesis Study. While the study has not yet been published, Dr. Lipkin pointed out this research suggests that

immune activation, which likely sets off symptoms of ME/CFS, might be triggered by gut microbiomes. He provides additional information about the role of gut microbiomes, how they may be treated, and what needs to happen next to move this research forward.

Read more about the role of the microbiome and its hypothesized link to ME/CFS in this article, "[Gut bugs misbehaving? The microbiome and ME/CFS](#)" (Phoenix Rising, dated January 13, 2014).

Coming at IACFS/ME Conference

Representatives from our Association will be at the IACFS/ME conference in San Francisco March 20-23, 2014. One of the sessions we will be attending is called the "**Immunology Primer for Practitioners**"

chaired by Dr. Daniel Peterson.

[As described by Simmaron Research](#)

, "Its mission: to produce bulletproof recommendations for immune tests that will guide both the diagnosis and treatment of chronic fatigue syndrome... Besides the recommendations, the Workshop will provide education for clinicians on the immune system in ME/CFS, overviews of immune findings, and insights into cutting-edge ME/CFS immunological research.

"This is a Workshop that could change how Chronic Fatigue Syndrome patients are tested and treated in the upcoming years... Standard immune tests for ME/CFS patients could change viewpoints and unlock new treatment opportunities for many."

Also at the IACFS/ME Conference, the long-awaited revisions to the 2012 ME/CFS: Primer for Clinical Practitioners will be released. The 2014 edition contains updated research and clinical information as well as an expanded section on the severely ill.

From the Netherlands — Broadcasting Science to Patients 2014

A series of 7 videos with Dr. Nigel Speight, Consultant Paediatrician for the University Hospital of North Durham, UK., with transcripts has just been released by ME/cvs Vereniging. In the first video Dr. Speight discusses his involvement in law suits regarding children with ME. Other segments discuss both general information and information specific to ME in children.

These continue the video series which began with a variety of ME/CFS topics by Dr. K. DeMeirleir, and continued with topics on cardiology by Dr. F. C. Visser. These videos are short (most are under 10 minutes), contain excellent content, and are very much worth the time to watch (or read). Links to the entire series can be found on the organization's [English page](#) .

Permission to disseminate all transcripts within the project Wetenschap voor Patiënten (Science to Patients), is granted under the explicit condition that the source, ME/cvs Vereniging (<http://www.me-cvsvereniging.nl/>) is clearly mentioned.

Social media and Support

[HealClick.com](#) is a newly launched message board and forum which matches patients with other patients based on their shared symptoms, conditions, and treatments. Furthermore, health data is submitted to scientists to help promote research. HealClick focuses on patients with ME/CFS, Fibromyalgia, Lyme Disease, Lupus, Rheumatoid Arthritis and related conditions. HealClick also has a [blog with a section devoted to ME/CFS](#) .

Sharing and support sites like this may be useful to patients who are not able to attend in-person support groups. Before you join, be sure to read the Terms of Use and Privacy Policy. To learn more, view the [introductory video](#) .

Love and Fatigue in America, an autobiographical novel about British author Roger King's experience being ill with ME, is now available in paperback as well as Audible and Kindle editions. Mr. King currently lives in Massachusetts and has done two well-attended and (dare we say) entertaining readings for our Association. This book has a 5-star rating on Amazon (well, 4.8). This "funny, sad, and thought-provoking" novel appeals to patients and also gives valuable insights to families and friends of patients.

Fibromyalgia News & Developments

[VIDEO: How Fibromyalgia Is Often Under-Treated](#) (ProHealth)

Dr. Kevin White, an award-winning researcher, author and educator, is the featured speaker in this video (which is about 7 minutes long) which looks at the poor treatment received by many patients with fibromyalgia.

Advocacy News & Updates

Coming up March 11: Next CFSAC Webinar

The Chronic Fatigue Syndrome Advisory Committee will meet via webinar on March 11th from 12:00 pm to 5:00 pm (ET). The webinar instructions will be posted on the [CFSAC website](#) .

The Committee plans to hear Public Comments and Agency Reports which had been cancelled in December due to inclement weather. Additionally, the Committee will discuss recommendations to be presented by its “Education for CFS/ME” and “ME/CFS Researcher and Clinician-Scientist Recruitment” Workgroups.

If you'd like to have CFSAC notices and updates sent directly to your email address in future, you can sign up for the CFSAC listserv at http://www.hhs.gov/advcomcfs/cfsac_email_list.html .

Institute of Medicine Public Meeting, January 27, 2014

A [summary of the entire meeting](#) by Gabby Klein, with links to all meeting resources – videos, transcripts (where available), slides – is available on Phoenix Rising.

[Learn more about the Institute of Medicine Study](#)

Comments: Written comments are welcome at any time during the study. [Get more details here](#)

The Blue Ribbon project

Dr. Alan Gurwitt, a retired child psychiatrist and past president of our Association, now chair of our Medical Advisory Committee, was recently interviewed by Ryan Prior for the ME/CFS Documentary project. The film in the making, titled [The Blue Ribbon: ME/CFS and the Future of Medicine](#) , is billed as “a film that tells the great under-reported medical story of our time.” Production of the film was successfully funded by the ME/CFS community through [Kickstarter](#)

. Our Association hopes to provide screenings of this film around the state after its release – whether or not footage from Dr. Gurwitt’s interview is included!

[The Blue Ribbon Foundation](#) , among other initiatives, is now raising money to fund fellowships for medical students to work for one summer in ME/CFS research centers, with the goal of educating a future generation of doctors about this devastating illness.

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If you like receiving this free newsletter every month, please consider supporting the Association by becoming a [member](#) .

We also welcome [volunteers](#) , especially people with basic computer skills who would like to learn something new.

You don't need to live in Massachusetts, or be ill, to be part of our Association! We welcome healthy family members and friends, as well as patients, as both members and volunteers.

Please pass this newsletter on to family, friends, and fellow patients! If you are receiving this copy from a friend, you can [sign-up here](#) to receive the newsletter yourself.