

Announcement:

Sept, 2012

Position Paper in Support of the CFSAC Recommendations on the CDC CFS Toolkit and the IACFS/ME Primer

On September 10, 2012, an alliance of ME/CFS patient organizations and independent advocates submitted a position paper to the CDC in support of the June 2012 CFSAC recommendation to remove the CFS Toolkit and make the IACFS/ME Primer widely available. Our goal in submitting this joint position paper is to improve patient care by significantly improving the clinical guidance material available to medical providers, insurance companies, health clinics, secondary medical educators and patients.

For years, patients have expressed serious concerns with the content of the CDC CFS Toolkit because it fails to convey the seriousness of the disease, offers inadequate diagnostic guidance and even fails to acknowledge PEM as a hallmark symptom and focuses on CBT and GET for treatment. The Toolkit even states that the same clinical guidance is appropriate for both ME/CFS and "CFS-like illness" (chronic fatigue but without the 4 symptoms), blurring the line with other fatigue causes like depression. As a result, the CDC CFS Toolkit has miseducated medical providers and led to inadequate patient care, harmful clinical recommendations and patient stigma.

By comparison, the IACFS/ME Primer provides much more accurate and complete information about the pathology of ME/CFS and also provides extensive diagnostic and treatment information. As Steve Krafchick, CFSAC member stated, the IACFS/ME Primer is "a good, basic document that gives a primary care physician a real road map, whether it is to consider a differential diagnosis or different treatment options. There's nothing like it anywhere else".

Is it perfect? No. There are opportunities to improve it and the IACFS/ME has undertaken an effort to do just that. But as it is, the content of the Primer is far superior to the content of the Toolkit, providing both immediate benefits to medical providers and patients and also a significantly better baseline from which to make improvements over time.

It is for that reason that the alliance of ME/CFS patient organizations and independent patient advocates have jointly submitted this position paper to the CDC and requested that the CDC seriously consider this patient perspective as they consider what to do about the CFSAC recommendation. We have asked for a response to our recommendations by Oct 22, 2012.

You can access the position paper, toolkit and primer at the following links:

- CDC CFS Toolkit: <http://1.usa.gov/RRHPZW>
- IACFS/ME Primer: <http://bit.ly/TK6LEo>
- The full position paper: <http://bit.ly/TNStRJ>

If you have any questions or comments, do not hesitate to contact one of the following organizations and individuals who submitted this position paper.

ME/CFS Patient Organizations

[Chronic Fatigue Syndrome, Fibromyalgia and Chemical Sensitivity Coalition of Chicago](#) , [Coalition 4 ME/CFS](#)

,
[The Connecticut CFIDS & FM Association, Inc](#)

,
[Massachusetts CFIDS/ME & FM Association, Inc.](#),
Mothers against ME

,
[New Jersey CFS Association, Inc.](#),
[PANDORA \(a.k.a. CFS Solutions of West Michigan](#)

),
[Phoenix Rising](#)

,
[Portland Fibromyalgia-ME/CFS](#)

,
[ProHealth](#)

,
[Rocky Mountain CFS/ME and FM Association](#)

,
[Speak Up About ME](#)

,
[Vermont CFIDS Association, Inc.](#)

,
[Wisconsin ME/CFS Association, Inc.](#)

ME/CFS Patient Advocates

Rich Carson
Lori Chapo-Kroger, R.N.
Lori Clovis
Mary Dimmock
Pat Fero, MEPD

Joan Grobstein, M.D.
Jean Harrison
Cort Johnson
Patricia LaRosa, R.N., MSN
Denise Lopez-Majano
Billie Moore
Mike Munoz
Matina Nicolson
Donna Pearson
Mary Schweitzer, Ph.D.
Meghan Shannon
Rivka Solomon
Jennifer Spotila, J.D.
Tamara Staples
Patty Strunk