

# The CFIDS Association of America

*Working to make CFS widely understood, diagnosable, curable and preventable*

**Kim McCleary**  
*President & CEO*

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Dear Friend of the CFIDS Association,

In 1987, the CFIDS Association of America began as a local support group in Charlotte, N.C. Two years later, a part-time administrative assistant was hired, and in early 1991, I joined a staff of four young professionals. Each of us was drawn to the cause by a genuine desire to make a difference in the lives of people we knew with CFS. Nearly two decades later, two of those four people are still motivated every day by that same desire – CFO Kris Hopkins and me – as are the other seven members of the Association’s staff.

My passion for the work of the CFIDS Association has grown more intense with each person I’ve met who has shared her or his story about how CFS has devastated a life. Six years ago, I married a man whose mother and sister have CFS, adding a very personal dimension to the fight I’ve made my life’s work. But from the beginning, being part of the CFIDS Association has been about conquering CFS – making it widely understood, diagnosable, curable and preventable. This is the mission we have sustained together for 22 years, under the leadership of a dedicated volunteer Board of Directors of individuals personally affected by CFS and with the support of generous donors at all levels. This is the mission that will guide us until CFS has been conquered.

While our mission remains unchanged, the organization has evolved over the past 22 years. We’ve used collaboration whenever possible and confrontation when necessary. We’ve formed alliances and partnerships when helpful, but refused to dilute our focus or compromise our integrity. We’ve seized opportunities to expand high-quality research, educate medical providers, influence public opinion and change public policy, all with the goal of improving the everyday lives of CFS patients. At times of uncertainty, tension and dissension, we’ve tried to hold a steady course, a pledge that has taken on renewed importance since the announcement of the XMRV discovery two months ago.

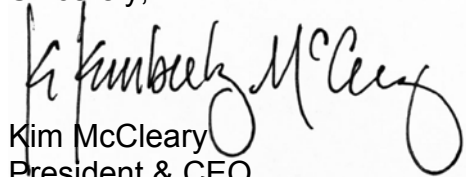
As a family member of two people affected by CFS, I know first-hand the range of emotions generated by this and other research announcements. “Finally,” patients say and their loved ones echo, “a potential cause has been identified, a discovery that brings us closer to an effective treatment or even a cure.” The link between CFS and XMRV is the most recent promising news of this kind, and I hope and pray it will take us farther than we have been before.

Upon the October 8, 2009 publication of the XMRV study, the CFIDS Association congratulated Dr. Judy Mikovits and her colleagues at the Whittemore Peterson Institute, Cleveland Clinic and the National Institutes of Health. Since then, we have advocated vigorously for research to explore these findings more deeply and we have provided regular updates in an effort to meet the unprecedented interest in new developments. We are expanding our efforts; in the coming weeks and months, the CFIDS Association will:

- continue to share news and frequent updates about XMRV and other high-interest topics through our website ([www.cfids.org](http://www.cfids.org)), our Facebook page ([www.facebook.com/cfidsassn](http://www.facebook.com/cfidsassn)), our electronic newsletter (CFIDS*Link*) and our print publication, *SolveCFS*;
- announce new opportunities for patients and loved ones to participate directly in innovative research projects;
- participate directly in the new Blood XMRV Working Group formed by the U.S. Department of Health and Human Services to address high-priority studies of this retrovirus in human disease and potential risks to the general blood supply;
- educate members of Congress and other health policy makers about the urgent and unique opportunities in CFS research and the need to translate these opportunities to advances in improved diagnostics and care; and,
- launch of series of webinars bringing CFS experts to you through the internet.

Every person whose life has been touched by CFS eagerly awaits research that will produce what we so desperately desire: absolute validation, definitive answers and unbridled hope. As a community, we must mobilize energy and accelerate momentum. We must unite as never before to champion ample rigorous science that dispels all doubt and returns all women, men and children with CFS to healthy, productive lives.

Sincerely,



Kim McCleary  
President & CEO

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