Testimony

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It has been almost 30 years since people in small towns around Reno, Nevada and in rural western New York state came to the attention of their local physicians. At first these patients were typical of other patients with routine, acute flu-like illnesses, the type that get casually written off as being "just a virus." But when they failed to recover after weeks and then months, it was clear that their illness was more than just routine.

Over those 30 years, there has been a lot of water under bridge for CFS. Just like the mighty Mississippi, with some regularity, that water has overflowed its banks – kind of like it's doing right now.

I don't believe there is a person seated at this table or in this room or watching from home via webcast who doesn't understand why there is so much anger, disappointment, discouragement and downright despair within the CFS community right now. For those who have watched and waited and held out hope for answers to relatively simple questions about CFS for years or for decades, the sustained lack of clarity about the role of XMRV and other murine leukemia virus-related viruses is just the latest example of research that has so far failed to deliver.

But rigorous research is the only route to answers and the only route to improve the methods by which CFS can be detected, diagnosed, treated, cured and prevented. Engaging more researchers from a broad array of disciplines and backgrounds is absolutely essential to understanding this disease and its complexities.

Last month's State of the Knowledge Workshop demonstrated how much has been learned about CFS over these 30 years, but how little that knowledge has translated to better care for CFS patients.

If you get down to it, the approach to caring for CFS patients actually hasn't changed much since Dan Peterson, Paul Cheney and David Bell saw their first patients in Incline Village and Lyndonville, NY three decades ago. It hasn't even changed much since the case reports written a century ago about neurasthenia or Iceland disease or myalgic encephalomyelitis or La Chose, or any of the other names that have been used to describe very similar post-viral illnesses. That's why the CFIDS Association has prioritized research in its latest Request for Applications that will lead to improved treatment. Because for all things about which there is no agreement in the CFS community, the need for better treatments is uniformly embraced.

Before I close, I want to make one point very clear. The CFIDS Association stands for rigorous research that leads to better care for CFS patients. The results of NIH-supported research into XMRV will provide answers about whether XMRV is a route to

better care. We will support the outcome of those studies, whichever way they lead. We will continue to foster the engagement of scientists interested in viral hypotheses and other well-reasoned approaches to improving diagnosis and treatment.

There is a lot of water under the bridge. Like any other disaster relief effort, CFS demands ample resources and leadership from federal agencies, organizations large and small and help from individuals, willing to pick up a sandbag or a shovel to help their neighbor. We simply must mobilize and scale our response to meet the challenge of CFS head-on. The people seated around this table can make sure that happens.