

## **2016 Special Service Award: Cort Johnson, MS**

Presented by Dr. Fred Friedberg

Cort Johnson came down with chronic fatigue syndrome/fibromyalgia around 1980 while at the University of Santa Cruz. He received a BA in Philosophy from Cal State Long Beach in the late 1980's and a MS in Environmental Studies from San Jose State University in 2000.

Cort first created a content based website page on ME/CFS research and treatment in 2004 called Phoenix Rising. Soon afterwards a newsletter was added. By 2010 with the addition of a blog and a Forum package, and hundreds of articles and blogs later, Phoenix Rising had become the most visited ME/CFS website on the internet. In 2010, Phoenix Rising became a non-profit corporation.

Two years later, Cort left Phoenix Rising to form Health Rising. He has produced hundreds of blogs on CFS and Fibromyalgia. On a more personal note, Cort set up a blog focused on our IACFS/ME Fatigue journal -- when news of the future journal first began circulating in 2012. The new journal received close to 100 comments on Cort's site --apparently one the most blogged topics at the time. I got a first-hand look at how many patients felt about the new journal and it wasn't always complimentary. But it also gave me a sense of some of the challenges that the journal faced and so the feedback was helpful and much appreciated.

Cort is the quintessential patient advocate, breaking more news about this illness than many professional journalists. He has an amazing ability to absorb complex medical information and translate it into user friendly language for his readers and the CFS/ME community. You can rely on him to keep patients updated with the latest information about the illness. His reports provide hope, which is so important and often hard to find with the minimal attention this disorder has received through the years. His commitment to science as well as courtesy is a refreshingly welcome approach that is respected by patients and professionals alike.

Some comments from patients about Cort's writings on Health Rising.

His letters are both clear and informative. When I think of Cort's work for the patient community, I think Education, Balanced reporting and Science.

He has given us, the average patient, a voice. That was and is still, for me, something of a miracle. CFS sufferers around the world are indebted.

He writes so clearly and is always thoughtful about the information. Those of us that struggle with this frustrating, little understood disease need advocates like Cort. He is a beacon of articulate strength – not to put too much pressure on you.

I'd like to present our first 2016 IACFS/ME Special Service Award to Cort Johnson.