President's Letter - February 2011

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The past year was a very busy and interesting year. While there were disappointments on the national scene there have also been many advances: in scientific research; in the awakening of some governments to the toll of CFS/ME on their citizens; and the rising up of PWCs, fed up with the continued dithering on the part of political and scientific "leaders", to become more active as advocates. These are all interconnected.

The last mentioned first. There has been a groundswell of calls for more and more assertive advocacy on the behalf of people with CFS/ME. One triggering factor was on the science front: the publication of the paper from the Whittemore Peterson Institute (WPI) on XMRV in CFS/ME patients published in SCIENCE in October 2009 and all the related events that followed. Although less dramatic, there had been much progress over the last several years in understanding both what goes wrong (pathophysiology) in CFS/ME and the possible biological and chemical triggers. However the big impact of the WPI paper (along with the National Cancer Institute and the Cleveland Clinic) was stunning. Whether or not the findings stand up over time there was at last new and widespread interest around the globe. It seemed as though the progress and volume of scientific research quickened.

The CFSAC meeting in Washington in October 2010 was another occasion for the gathering of scientists and advocates enabling vigorous discussion and debate. A small group of activists meeting separately with officials in Washington in early autumn turned up pressure on the National Institutes of Health (NIH).

Whatever the reasons, key leaders at the NIH are responding and making statements and taking actions to increase research efforts and to involve patient representation. In early April (2011) NIH will be sponsoring a two day State of Knowledge conference. The steering committee to develop the conference includes two patient advocates (Pat Fero and Mary Schweitzer) invited by Dennis Mangan (Ph.D.) of NIH who has replaced Dr. Hanna. Dr. Mangan made his selection from a list provided by the patient organization P.A.N.D.O.R.A.

New waves of advocacy

Towards the end of 2010 the first ever ad, placed in the Washington Post by P.A.N.D.O.R.A. and co-sponsored by 4 regional American CFS/ME organizations, urged the public to note the discovery of a "new" potential pathogen (XMRV), perhaps present in donated blood from CFS patients, and to join in the call for urgent and more active research. MassCFIDS decided not to join in this effort as we thought there was some scientific inaccuracy in the ad but we applauded the intention to not remain invisible.

The new wave of advocacy was not limited to the U.S.A. A few examples. In February of 2010 the first CFS/ME patient group in Japan was started by a Japanese woman who became ill while living in the United States. Again in the summer of 2010 we were contacted by the head of a relatively new patient group in Germany. She asked us and Dr. Anthony Komaroff for permission to translate and disseminate the lecture given by Dr. Komaroff at the conference sponsored by us in April 2010. Permission was given, the translation accomplished and then distributed. Quite recently, in Spain and its Catalan region, an advocacy group has made great progress in urging an increase in funding for research and clinical services.
During 2010, with so many questions about XMRV including about how it is transmitted, several countries decided to restrict CFS/ME patients from donating blood. New Zealand, Australia, Canada were early deciders. Here in the United States 2 key blood bank organizations did the same.

Why all this activity now? I am reminded of a short essay I wrote about a year and a half ago entitled "When is enough enough?" Perhaps the "enough is enough" point has been reached, first encouraged by scientific breakthroughs creating a hope for emancipation from this illness-caused imprisonment, contrasted with continued inexplicable intransigence at the CDC and elsewhere. It was as though a collective burst of determination was triggered saying, in effect, we won't be pushed aside again, and you, CDC and NIH, must get moving on the science.

We won't let "you" continue to underfund the WPI, undercut responsible researchers, sponsor various committee meetings that are nothing but sops to quiet the restless, and continue the inane psychologizing of CFS/ME. We all need to say enough is enough. Not only do we need and want better science but, just as important, a very big change in attitude on the part of researchers and clinicians.

XMRV News

As to the scientific advances, perhaps you have been following the back and forth controversy about last year's paper in SCIENCE concerning the finding of the presence of a relatively recently discovered third retrovirus labeled XMRV in CFS/ME patients. Attempts at replication have been done, with negative results in most studies but positive results in a key NIH study. Problems with replication attempts have included differing criteria for categorizing patients as having CFS/ME, and differing laboratory procedures (reagents used, limiting detection to PCR only, etc.).

As I write this letter there have been further claims that mouse biological contaminants have clouded findings. I am not speaking for our Association in my own personal conclusion, based on close following of information from the Whittemore Peterson Institute and a talk by Judy Mikovits, Ph.D. in October of this year, that the original findings still seem valid and that mouse contamination was probably not involved. There was never any claim by the WPI and their colleagues that XMRV was/is a causative factor, merely that in the patient population studied a large number of CFS/ME patients harbored XMRV. However, whether or not the family of retroviruses initially called XMRV is a significant infectious agent in CFS/ME, only further research can provide answers. That is the basis of the new sense of urgency, the renewed advocacy, but only one of many reasons why much better funding and focus on CFS/ME research is needed not only in our country but in others as well.

Yes, increased advocacy is indeed needed and needed now.

To join the new advocacy efforts, our Association has established a new advocacy/outreach committee. You will be hearing from them in this year as soon as they have mapped out their plans. Suggestions and help are welcome.