

President's Letter, Early Fall 2010

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Fall conference on October 30th

We will be sponsoring the second educational conference of the year on Saturday afternoon, October 30th. Rik Carlson, president of the Vermont CFIDS Association, and Michael Thurston, videographer, together have made a powerful film called “INVISIBLE,” which shows what patients with Chronic Fatigue Syndrome (CFS) experience, how they manage their lives, and the impact of the illness on their families and social structures.

The two filmmakers will join us when we screen their film and then discuss it with them and among ourselves. What are the pertinent issues and what can we, individuals and groups such as our Association, do about tackling those issues? We think there is much that can be learned from this film and much that each one of us can do, individually and together, in the future. Please join us for a thoughtful movie and discussion. This is an excellent program to share with friends and family. Please invite others to come with you. The event is free and open to the public. You can register now.

There is a change of location for this conference. We will be meeting at the Morse Institute Library in Natick, in the Lebowitz Meeting Room on the ground floor. Registration starts at 12:30 and the film screening will start at 1:00 PM. The discussion will end by 3:30. See our announcement for further details. Please help us publicize this program by downloading and printing our flier (link is on the Announcement page).

Spring 2011 Conference

Dr. David Bell, a national (and international) expert on CFIDS in children and adolescents, will speak to us in the spring. We will keep you informed.

Research update

As shown on our website, the month of August was a busy one in the research news department. I won't review all of the news here. The recent paper from the National Institutes of Health (NIH) on retroviruses and CFS (Alter, et al.), which received much attention from prominent new media, partially confirms the Whittemore-Peterson Institute findings of a retrovirus being present in many of the CFS patients tested but raises many questions about which retrovirus or retroviruses are involved. Furthermore there is no confirmation of the possibility that such a retrovirus is a cause of CFS. I think it will probably take much time and continued effort to sort out the complex scientific issues so we must still be patient. The good news is that many key researchers and research organizations are involved now, including the infectious disease people at the NIH.

In a possibly related matter, the CDC has been advertising for a new director of their CFS research section. This could be a forward step, but as we all have learned, the CDC has to be closely monitored. Speaking of monitoring the federal medical science branches, a stalwart group of nine PWC advocates, including Rivka Solomon of Massachusetts, met with some key people at NIH basically asking why NIH had not been more consistently involved and pointing out the ways and goals most needed. The problem here is not only re-directing research funding but, if possible, changing the attitudes of both the researchers and chief administrators. The skeptical and denigrating attitudes are no longer acceptable. These nine PWC's plan to meet with the NIH officials again in three months to monitor progress.

Volunteer news

We are very gratified by your responses to our requests for volunteers to help out. Ours is an all volunteer organization. What we can or can't do depends on who steps forward even if it is just a couple of hours a month. For example, over the next 12 months we hope to increase our outreach to legislators (state and federal) and state departments of health and education. We also need to increase our fundraising. There is no way we can do either of these without adding volunteers to learn about and focus on these tasks. We have created a new Volunteers Committee to revamp not only our recruiting but also our training, assignment,

supervision and retention of volunteers. If you can help out, please contact us.

Membership

Your membership in the Association is extremely important. Although membership contributions help us meet our basic expenses (e.g. keeping us 'on the air' via our website), your membership is even more important in giving patients a strong voice through our Association. If you are not already a member of the Association, please consider joining. Courtesy memberships are available.

We look forward to seeing you on October 30th!