

This year marks the 18th year for an International May 12th Awareness Day. A member of a Toronto based advocacy group was inspired by the work done by Rachel (<http://meaware.wordpress.com/2010/02/18/10-things-about-mecfs-awareness/> and <http://Blogging-for-MECFS-Awareness/323408389280?ref=ts>) to write the following document on May 12<sup>th</sup> Awareness Day. We hope it will inspire you to do whatever you can to help spread the word and make May 12, 2010 a day to remember.

## MAY 12<sup>th</sup> International Awareness Day

*“If a cause and cure are to be found for ME/CFS, FM, MCS and related illnesses in the near future, government and medicine must be made fully aware of their scope and impact. Despite the efforts of a number of dedicated groups and individuals, there are still vast pockets of ignorance and misunderstanding. To this day, many patients run directly into a medical establishment that, in general, knows very little about these serious threats to human health. It is therefore crucial that all those affected by the illnesses make their voices heard, especially on May 12th of each year.”*

[RESCIND. INC. org]

This year, 2010, marks the 18th year for an International May 12th Awareness Day. The idea originated with Tom Hennessy, the founder of RESCIND, Inc. (Repeal Existing Stereotypes about Chronic Immunological and Neurological Diseases). Mr. Hennessy was based in the US but understood that it needed to be an International event. He designated May 12 as the International Awareness Day for the spectrum of illnesses he called Chronic Immunological and Neurological Diseases (CIND).

May 12 was chosen as it coincided with the birth date of Florence Nightingale, the English army nurse who inspired the founding of the International Red Cross. Nightingale became chronically ill in her mid-thirties with a Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)-like illness. She was often bedridden for the last 50 years of her life. Despite suffering from a debilitating illness, she managed to found the world's first School of Nursing.

Mr. Hennessy included ME/CFS (also known as Chronic Fatigue and Immune Dysfunction Syndrome -- CFIDS), Fibromyalgia, Multiple Chemical Sensitivity and Gulf War Syndrome under the CIND umbrella. These illnesses, characterized by cognitive problems, chronic muscle and joint pain, extremely poor stamina, and numerous other symptoms, afflict people around the world in alarming numbers.

May 12 efforts have largely been grassroots and undertaken by individuals or individual organizations. Due to the mandates of these organizations, the awareness efforts have, for the most part, focussed on only one of the illnesses.

From the beginning in 1993, various ME/CFS organizations were behind the idea. Early support came from a UK group called BRAME (Blue Ribbon Awareness for the awareness of Myalgic Encephalomyelitis). They highlighted the May 12th International Awareness Day at a World Medical Conference on ME/CFS in 1995. This was instrumental in the campaign being adopted internationally for ME/CFS.

Efforts by Fibromyalgia organizations took a little longer and efforts by MCS groups have been limited. National FM efforts in the United States started in 1997 with the National Fibromyalgia Association (NFA). Multiple Chemical Sensitivity and Environmental Sensitivity groups have for the most part not taken up the day, although there have been some in the US who have used the month of May to raise awareness for Multiple Chemical Sensitivity and Toxic Injury Awareness.

In Canada, through the efforts of the then newly founded (June 1993) National ME/FM Action Network, May 12th has been an Awareness Day since 1994. The first year it was only for ME/CFS but from 1995 and onward it has been for both ME/CFS and for FM. On May 12, 1996, Parliament declared a National Awareness Day for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia. In 2006, the Senate proclaimed May 12 to be a National Awareness Day for Fibromyalgia and ME/CFS. This action was taken through the efforts of Senator Dr. Wilbert Keon and of FM-CFS Canada (established Feb, 1996).

Some organizations have an International ME/CFS Awareness Day (May 12), others have a week (this year, May 9-15), still others, such as the newly formed European ME Alliance which includes 9 European countries, use the whole month of May. In Canada, May 12 is included in Health Canada's Calendar of Health Promotion Days as "Fibromyalgia and Chronic Fatigue Syndrome National Awareness Day". Awareness activities also occur in Australia and New Zealand.

Canadian efforts have been undertaken by the National ME/FM Action Network, by FM-CFS Canada, by provincial organizations and by local support groups. The following has taken place in the Ontario legislature:

1. in 1994, through the efforts of the Myalgic Encephalomyelitis Association of Ontario (MEAO – founded in 1991) May 12th was recognized and it was recognized as the second International public awareness day for Myalgic Encephalomyelitis (Chronic Fatigue Syndrome).
2. in 2003, again through MEAO, another Member's statement was made on ME/CFS Awareness and blue ribbons were worn by the MPPs.
3. in 2005, through the efforts of FM-CFS Canada, May 12 was recognized as a National Awareness day for Fibromyalgia and Chronic Fatigue Syndrome and the first national campaign being undertaken by FM-CFS Canada was also recognized.
4. In 2008, a member's statement, organized by the York region fibromyalgia and CFS wellness support group, was made recognizing Fibromyalgia and ME/CFS and,
5. In 2009 another awareness statement on Fibromyalgia and ME/CFS was made through the efforts of FM-CFS Canada.

Many cities across Canada have proclaimed May 12 ME/CFS and Fibromyalgia Awareness Days and many individual support groups have organized May 12 Awareness activities.

#### Purpose of Day and Need for Action

ME/CFS & Fibromyalgia Awareness Day activities are designed to increase public awareness of ME/CFS and Fibromyalgia and chronic pain illnesses, as well as to assist patients, patient support groups and organizations in educating the general public, healthcare professionals, government officials, and legislative bodies.

If you need to know why spreading awareness of ME/CFS, Fibromyalgia and MCS and related conditions is important you only need to have a look at the Statistics.

[http://mefmaction.com/images/stories/quest\\_newsletters/Quest80springsummer2009.pdf](http://mefmaction.com/images/stories/quest_newsletters/Quest80springsummer2009.pdf)

#### Tom Hennessy Jr. Interview

In 2008, Cort Johnson of Phoenix Rising (<http://www.aboutmecfs.org/>), did an interview with Tom Hennessy Jr. about his role in the founding of May 12 and RESCIND, Inc. As Cort notes, Tom was a former advertising executive and is a very articulate advocate. He developed RESCIND (<http://www.rescindinc.org/>) as a virtual lobbying group. Unfortunately Tom has been disabled for many years with a horrendous case of ME/CFS and, to add insult to injury, it has been reported that he was critically injured in a car accident in Florida in 2009 and is still recovering in a nursing home. This is an excerpt from the interview:

*"I wanted to pick a spring or fall day for our "awareness/lobby" day. Most of us really sick ME patients are too ill to leave our homes most days and we just can't go outside or on a trip to D.C. in the summer or winter months. I also wanted it to be International. May 12th is still bigger overseas than the US. ...*

*After reading Byron Hyde's [founder of the Nightingale Foundation] great book on the history of Myalgic Encephalomyelitis, I decided to look up his hero's Birthday, and lo and behold, May 12th, was Florence Nightingale's birthday. ... She contracted an M.E. type illness (thought to be brucellosis) at age 35 and she was bedridden for the next 50 years. I decided that her birthday May 12th would be the day."*

#### Recent awareness raising groups include:

- WAMCARE (Worldwide Association for ME/CFS Awareness and Research <http://www.wamcare.org/index.html>) was formed in 2009 and they use social media to spread awareness for ME/CFS. They are active on Face book, Twitter and Live Journal
- The Blue Ribbon Campaign established by Andrea Martell (from Ottawa) [http://www.blueribboncampaignforme.org/What\\_You\\_Can\\_Do.html](http://www.blueribboncampaignforme.org/What_You_Can_Do.html) was also formed in 2009 and is a campaign to raise awareness for ME/CFS. One of their activities this year is a Facebook event to display a blue ribbon as your avatar on May 12th 2010 <http://www.facebook.com/event.php?eid=83125971055>

- An innovative Facebook group focussed on May 12th is working to improve the sharing of May 12th ideas -- May 12th is International Awareness day for ME/CFS and FM. Share your plans for May 12th and get involved to help spread awareness on May 12th.  
<http://www.facebook.com/pages/May-12th-International-MECFS-FM-Awareness-Day/220534562160>
- <http://meaware.wordpress.com/2010/02/15/blogging-for-mecfs-awareness-2010/> -- is asking participants to blog for ME/CFS awareness and is posting a list and links to their blogs on this site.

## Ribbons

Ribbons are used by many groups as symbols of support or awareness. The ribbon colour used for ME/CFS is blue, for Fibromyalgia it is purple and for MCS it is green. In all cases, the ribbon colour is not unique to the cause but is used for other causes as well.

The use of the blue ribbon for ME goes back to 1995 and BRAME (Blue Ribbon Awareness for the awareness of Myalgic Encephalomyelitis. As previously noted, they highlighted the May 12th International Awareness Day at a World Medical Conference on ME/CFS in 1995 and as a result were instrumental in the ME/CFS Awareness campaign being adopted internationally.

The blue ribbon was worn by MPP's in the Ontario legislature in 2003. A more recent attempt to raise awareness and the blue ribbon is being made through a virtual, blue ribbon campaign for ME (<http://www.blueribboncampaignforme.org> ).

It is fitting that the purple ribbon has been adopted for Fibromyalgia awareness. It has been used for many years to bring awareness to women's issues and to a number of health issues. In Canada, over 80% of those suffering from Fibromyalgia are female. This is the highest percent of any chronic condition.

Green ribbons have been adopted by those with Multiple Chemical Sensitivity and those with Environmental sensitivity. As well as for other causes, this colour ribbon is also used for Environmental protection and for Lyme disease awareness.

One MCS campaign, originating in Hawaii, in February 2010 with website aptly called the canary report, is using yellow to represent the canary.

## Other groups using May 12

As a bit of trivia, the Awareness Day of May 12th is also shared with Canada Health Day and International Nurses Day (also because of Florence Nightingale's birthday). It is also shared by Limerick Day to celebrate the birthday of Edward Lear whose Book of Nonsense did much to popularize this form of verse.

WEB addresses and sources for May 12<sup>th</sup> or ribbons:

1. The National ME/FM Action Network  
[http://mefmaction.com/index.php?option=com\\_content&view=article&id=274&Itemid=283](http://mefmaction.com/index.php?option=com_content&view=article&id=274&Itemid=283)
2. FM-CFS Canada – Compassion in Action <http://fm-cfs.ca/may12.html>
3. <http://meaware.wordpress.com/2010/02/15/blogging-for-mecfs-awareness-2010/>  
From a drawing Rachel, the site's creator, did in 2007 there is:  
<http://rachelcreative.wordpress.com/2008/04/18/banners-for-mecfs-international-awareness-day/>
4. Blue Ribbon Awareness for Myalgic Encephalomyelitis: <http://www.brame.org/>
5. RESCIND, Inc.: <http://www.rescindinc.org/>
6. Phoenix Rising and the Interviews: <http://aboutmecfs.org/Int/IntHennesseyCFS.aspx>  
<http://aboutmecfs.org/HeadPgs/Interviews.aspx>
7. European ME Alliance: <http://www.investinme.org/index.html> The alliance was formed in 2008 and now consists of national charities and organisations from Belgium, Denmark, Germany, Ireland, Norway, Spain, Sweden, Switzerland and the UK.
8. <http://www.fightingfatigue.org/> [Contains some background information about May 12 – Two pages in particular ?p=1409 and ?p5987]
9. New Zealand info/advocacy package from 1995 – still some relevance  
<http://www.ncf.ca/ip/social.services/cfseir/may12/may1295.html>
10. Fibromyalgia Groups [www.fmaware.org/site/News2?page=NewsArticle&id=8185](http://www.fmaware.org/site/News2?page=NewsArticle&id=8185)
11. Multiple Chemical Sensitivity groups <http://www.americanchronicle.com/articles/view/139302> article by Lourdes Salvador of <http://www.mcs-america.org/>
12. Green ribbon -- <http://www.wtv-zone.com/infchoice/mcsposters.html>

This document was created by a member of the ME-FM-MCS Patient Advocacy Group

Email: [ME-FM-MCS-Patient-Advocacy-Group@bell.net](mailto:ME-FM-MCS-Patient-Advocacy-Group@bell.net)