Newsletter January 2006

INVEST in ME
No.06/01 / January 2006
NEWSLETTER

Welcome to the **Invest in ME Newsletter** for January 2006.

A belated Happy New Year to everyone.

Since the December Newsletter was published there have been a few developments for IiME. Our community has expanded due to more awareness of our existence. Special thanks to those who have introduced us to so many more people from around the world.

ME Awareness is the theme of this month's newsletter. The year of 2006 could be the most defining yet for the ME community. The Gibson Inquiry will be reporting this year. Our aims of *education about*, *publicising of* and *lobbying for* awareness of Myalgic Encephalomyelitis are encapsulated in the ME Conference 2006 in London on ME Awareness Day.

The conference has attracted wide interest and we hope we are able to see Pwme at the event, although it is appreciated that this will be difficult for many. See news later on regarding this event.

IN THIS ISSUE

For 2006 to be a pivotal year for ME means that, unfortunately, the ME community has to convince people to listen. This means constantly using every means possible to attract attention and raise awareness. The ME and My MP campaign is still going and MPs should be one of our first targets for support. We have also added a page on the Tayler family's experience to raise more funding for biomedical research.

One of IiME's objectives is for adoption of the Canadian guidelines for clinical diagnosis of ME. Recent additions to the documentation has resulted in a more condensed overview of these criteria which will make it easier for healthcare staff to use. The new link is added to our Info Centre Guidelines page. The overview of the Canadian Consensus Documents has been co-written by Dr. Bruce Carruthers. Dr. Carruthers will be at our London ME conference in May.

The Invest in ME site has been viewed from an increasing number of countries (indicated by the flags below). Although it is wonderful to be connected with so many contacts from other countries the flip side to this is a more sombre realisation that ME knows no boundaries and is affecting people around the world. We hope we may link up with other international and regional organisations. The more we co-operate and join forces the more focused our efforts can become.

We can all make a difference.

News of Invest in ME 1 - Regional Contacts

In the December Newsletter we mentioned our regional contacts - Flora McKenzie, Debbie Hughes and Audrey Irving. We would also like to add this month Carol Ashcroft who is covering the north of England and Anne Gosling who is in Dundee. We feature our regional contacts on the web site. In the meantime, if you would like to help us as a regional contact please write to us via this link.

News of Invest in ME 2 - Our Logo

A new year and a new logo. In line with our belief that funding for biomedical research is the only way to find a cure for ME we have wrapped a double-helix around our organisation's name to produce our logo. The double-helix logo will now appear more frequently on all of our publications and on our web site.

The ME CONFERENCE 2006

For M.E. Awareness Day 2006

Invest In ME

are proud to announce

The ME CONFERENCE 2006

An UPDATE on Clinical Diagnosis,

Research Trends and Educational Support

The Invest in ME conference in London on 12th May has attracted a great deal of interest - not only from within the UK but also from several other countries. We have delegates attending from several countries in Europe and have had interest also from USA and Canada.
One of our main objectives is to attract as many healthcare professionals as possible and we are pleased to announce that the conference has been awarded the **maximum Continuous Professional Development (CPD) points** by the Royal College of Paediatricians and Child Health and we'll shortly have that confirmed by other Royal Colleges. This allows healthcare staff to attend and claim the course as part of their career development. Educational and social services staff may also gain from this.

So, for those in the UK, please urge your GP, or paediatrician or local ME Centre staff to fill in an application form and attend and listen to the latest on clinical diagnoses, research trends and educational considerations from the people best placed to know.

The venue is One Birdcage Walk, Westminster, London, and a **registration form** (online or downloadable) is available **here** along with more details on the conference and presenters. A downloadable pack of documents will be available soon.

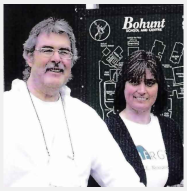
We are also pleased that **Dr. Betty Dowsett** is to attend the conference, as an honorary guest.

Events for 2006

Our events database is available for all groups and organisations and individuals who are interested in fund-raising for biomedical research into ME. The Events calendar has been updated for 2006 and it is there for everyone to use. If you know of events planned to support education on ME or fund-raising for biomedical research then please contact us with any news or information. Look in the Events page - see here.

Meridian TV – ME Expose

In last month's newsletter we were waiting for ITV to give permission to publish a series of programmes covering the effects of ME on severely affected patients.
Invest in ME has now been given that permission. The programmes contain interviews with ME sufferers in Hampshire as well as an official from the regional ME centre. Shocking, tragic and necessary viewing for your MP, GP, paediatrician or anyone interested in ME and the effect it can have on us all. View it here. Also included in these programmes is an interview with Dr. Jonathan Kerr.



The Tayler Family Fundraising Experience

Suzy Tayler's story is highlighted in the Meridian interviews. Her family embarked on an extended fund-raising drive last year culminating in over £8000 being raised for biomedical research.

ME Experiences

With ME Awareness Month just a few months away just another reminder that we would like to compile a listing of stories relating to ME. How you were diagnosed, the treatment and experiences you have had, the perception of others etc. We have two categories - persons with ME (pwme) and carers/parents of pwme.

If you would like to share your experiences then please contact us and let us know about you.

The gallery of stories for pwme is here. The gallery of pwme parents/carers is here.

Guest Speakers

Watch this space over the coming months for guest speakers.

Dr. Vance Spence and Dr. Betty Dowsett will be contributing articles to the Invest in ME site. We also have one or two interesting items coming up in the future. Our Guest Speaker page is located here.

The Gibson Inquiry

Submissions have been entered for the deadline set by Dr. Ian Gibson's Inquiry into ME. We had contacted Dr. Bruce Carruthers in December to ask if he had submitted anything for the Inquiry. Dr. Carruthers managed to submit information in time for the deadline - a valuable act for the ME community. Now we await news on the nominees for the committee examining the evidence submitted and interviewing interested parties. See here for news on the inquiry. Links to recent articles by Professor Malcolm Hooper have been added to the site.

Research News

More and more articles are appearing which link many illnesses, among them ME, with vaccines. We hope to be publishing more on these topics in the coming weeks as it is something which more researchers are discussing.
We have an article on the HHV6 virus which is also being linked to cases of ME. A recent discussion on a notice board was picked up and looked interesting so we created an overview. We later discovered a more in-depth article by Cort Johnson so we have also included a link to Cort's site. Read more here.

FINE Trials

Alice Burchfield contacted us recently regarding the FINE trials. If you ever worried that sorely-needed government funding for biomedical research might be being wasted or that the Medical Research Council might be looking the wrong way then don't stop worrying. Read Alice's story here.

ME and My MP Campaign

At the time of writing the status of the EDM 260/260A in parliament stood at 210/19. We have further contacts from MPs - some good, some less than good.

Anne Widdecombe had previously responded to our letter by signing EDM 260A. Norman Lamb (MP for Norwich)'s office has offered the possibility of tabling questions in parliament relating to ME. Although we are bound to be met by the same off-the-shelf answers normally provided by the government minister concerned it is still worthwhile keeping this pressure on. The ME and My MP campaign was started to attempt to make it easier to coordinate efforts to make MPs more aware of the issues with Myalgic Encephalomyelitis. We aim to write to five MPs per week asking for their support. Keep a regular eye on our campaign page and consider writing to your MP - we have a template letter on there to help you. We'll add your experiences to the responses gallery.

One thing MPs will learn is that we're not going away until ME is dealt with seriously in the UK. Eventually we will be in contact with every single MP.

Other ME Groups in the UK

We have to work together to be able to win this fight for publicly funded biomedical research into ME. So IiME is going to highlight what other groups are doing in the UK and how we can we work together.

The first in our series puts the focus on the ME Support Norfolk group. Go to our groups page here to see details of MES-N. This page will contain other groups over the next few months.

...and also Internationally

We have the same wish to be in contact, and hear about other groups around the world. So we shall be storing information and links to the other groups campaigning for the same issues as us.

...and Noticeboards

LocalME

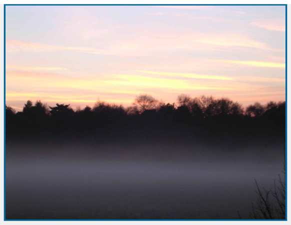
On our links page (click here) we have links to some areas which might be of use. One of these is LocalME, run by Connie Nelson. This is an interesting and friendly board where you can gain a lot of information, help and awareness of what is going on. Connie invites everyone to join the ME community here. You can sign up using this link. To subscribe just give your name and local group details in the email.
LocalME is meant for local support groups and everyone is welcome.

Invest in ME Campaign Badges

Still possible to get the original IiME campaign badge. All profits to biomedical research. Contact us to order.

We have added a RSS link to the home page. Read more on RSS here.

Contacts:



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