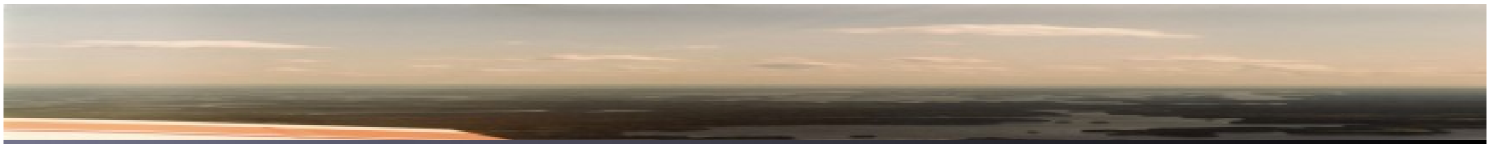

Newsletter December 2005

# INVEST in ME

NEWSLETTER

**No.05/01 / December 2005**

Welcome to the **Invest in ME Newsletter** for December 2005.

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This is our first newsletter by email and we would like to thank all of you who have signed up for this newsletter.

Invest in ME was formed at the start of the Autumn. Since then we have started working with people around the country and abroad to further our main aims - to educate, publicise and lobby regarding Myalgic Encephalomyelitis and the urgent requirement for public funding for biomedical research.

It may be December but the whole ME community needs to cooperate to raise awareness of the treatment of ME sufferers. So we are already looking ahead to an action filled ME Awareness Month. Our focal point is the ME Conference 2006 which we have organised for London on 12th May.

But there is more to be done. Look at our 5 simple things to do at the end of this newsletter. Simple things - but together they add up to more ME awareness.

2006 could be the most crucial year ever for ME. By working together we are sure we'll all make a difference.

All at Invest in ME will be working on more ideas in the New Year. Until then we all wish you a Happy Christmas and an ME-free New Year.

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## News of Invest in ME

IiME has established more regional contacts to help us coordinate activities. In the north we welcome Audrey Irving as a regional contact for Scotland. In the middle of England and covering Oxfordshire and surrounding area we welcome Flora McKenzie. For the South East of England we welcome Debbie Hughes. We shall be featuring our regional contacts on the web site in the future. In the meantime, if you would like to help us as a regional contact please write to us via this link.

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## Have a Cuppa for ME

The Have a Cuppa for ME events have now exceeded £4250 in fund-raising. This has occurred in a little over one month since Invest in ME initiated the idea. The objective with HACFME is to raise funds for biomedical research. The biomedical research charities, MERGE and CFSRF, are the main beneficiaries of this campaign.
Invest in ME hopes to begin a new round of HACFME in the New Year. Details can be found on our Have a Cuppa page - see here or at http://www.haveacuppaforme.org.

## 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.

Dr. Vance Spence from MERGE will be guest speaker at Invest in ME's in Hampshire on 18th Feb 2006 - see here.

The Events calendar has been updated for 2006. This is dependent on us being informed of events coming. Feel free to contact us if you have news of upcoming events. Look in the Events page - see here.

## The ME CONFERENCE 2006

Invest in ME has announced the biggest line up of experts on myalgic encephalomyelitis in one room in the UK for some years. The ME Conference in London, on 12th May 2006, is aimed at attracting healthcare professionals, social workers as well as ME sufferers together on one day to hear all about clinical diagnoses, research trends and educational considerations from the people best placed to know.

The venue is 1 Birdcage Walk, Westminster, London, and a **registration form** is available here for those interested in attending. Welcome to hear the real story behind ME.

## ME Awareness Month

In recent years any publicity in May has been focused within one week - ME Awareness Week. Now, every attempt at raising awareness of ME is to be applauded as the more publicity generated will make more people realise that there is a problem which needs to be resolved.

However, there hasn't been the coordination or focus which other similar campaigns (notably the McMillan campaign for breast cancer (Think Pink) attracted. So Invest in ME is attempting to make May 2006 **ME Awareness Month**. We feel only a whole month can raise the necessary awareness to generate a demand from the public and politicians that something has to be done.

Check our events page over the next few months to see what is being planned. The focal point will, as stated, be the ME Conference in London.

## The Gibson Inquiry

After initial enthusiasm toward Dr. Ian Gibson MP's announcement of an independent inquiry into ME there is now a sense of disquiet amongst some in the ME community

about the course which the inquiry seems to have taken. From the press release of 1st December 2005 there seem to be constraints being placed on people who will be involved, research which will be analysed and time allowed for people to make submissions. The deadline for submissions is 20th December.

See here for news on the inquiry

## ME and My MP Campaign

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 want MPs to support our efforts for biomedical research funding for ME both within parliament and within their constituencies.
So please take a while to look at our campaign page and consider writing to your MP - we have a template letter on there to help you. Follow the links and you can easily find your MP and contact him easily via email.

Thanks to IiME's regional contact for Oxfordshire - Flora McKenzie - the new Conservative party leader, David Cameron, has lent his support to ME sufferers. See our press release here. IiME have also had success in gaining the support of Norman Lamb, Henry Bellingham, Keith Simpson and Ann Widdecombe in recent months. We have also been in contact with Charles Kennedy to attempt to secure Liberal Democratic support for our campaign.

Eventually we will be in contact with every single MP.

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## ME Experiences – Your Story

We record some of the tragic stories of ME on our ME Stories pages. Although these stories bring home the effects of this debilitating illness they also show the resilience of ME sufferers and their families.

If you would like to share your experiences then please contact us.

The gallery of stories for ME sufferers is here.

The gallery of ME sufferers' parents/carers is here.

Coming soon will be the incredible year of fund-raising for ME performed by the parents and friends of Suzy Taylor.

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## Professor Malcolm Hooper Presentation Highlights

IIME and East Winchester ME Support recently invited Professor Malcolm Hooper to Hampshire to present Engaging With M.E. - a summary is available here.

It is worth re-iterating one of the key messages from the presentation -

**M.E. is a serious neurological illness not a psychiatric illness.**

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## Meridian TV – ME Expose

Meridian TV have aired a series of programmes covering the effects of ME on severely affected patients. A reporter from Meridian interviewed a number of ME sufferers in Hampshire as well as the regional ME centre.
This set of interviews has come nearest to conveying the suffering and lack of action regarding ME.
The interviews will be appearing on the Invest in ME web site soon. We are also asking if copies may be downloaded freely.

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## Opathy or Apathy

At this time, with the Gibson inquiry imminent, with our ME Conference in London in May being arranged and with the ME community showing increasing signs of becoming more active, then it is appropriate to just go back to basics and revisit, and finally put to bed, that debate which has been circulating this year - what does ME stand for?

Let's use one of Professor Hooper's remarks from his presentation **Engaging with ME** -

**"Encephalomyelitis", not encephalopathy, is the correct term, which is classified by the WHO. We should maintain the use of the current definitions of M.E. and also the use of Myalgic Encephalomyelitis"**

Look at our summary here.

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## 5 things to do this month

Here are ***5 things to do*** which can be performed during the next month to help make a difference in the campaign for biomedical research funding for ME.

1. Join our ME and My MP campaign - sign up to influence your MP- see here
2. Get a MERGE Box and fund biomedical research - put in your local shop, your post office or airport or railway station - even your doctor's surgery - see here
3. Contact us – let us know about you
4. Tell a friend about **Invest in ME**
5. Put the IIME web site on your Christmas cards/emails - http://www.investinme.org/

PayPal Donate Invest in ME uses Paypal

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## ME-baY

Coming to a web site near you - well, actually this web site.

We hope early next year to help you to help us to help us all by selling unwanted gifts, articles and other items via our ME-bay. The aim is to raise funds which go directly to biomedical research. So don't throw anything away this Christmas - there is a good home out there waiting your unwanted objects. And a worthwhile cause awaiting profits from the sale.

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And lastly - if you have that urge to get just one last-minute present for someone this Christmas then just spare another minute to look at our Christmas thought -

Merry Christmas

Contacts:

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