



NEWSLETTER

March 2007

Our apologies for the delay in distribution of our newsletter. The beginning of the year has been quite busy with meetings in London and the conference preparations and February has turned into March before we were ready with our February newsletter.

This is an update for all our friends to let you know how much we at Invest In ME appreciate your support. We realise that to maximise our effectiveness we need to keep you in the loop as to what we are doing and what we need to do together.

This last year has been incredibly busy and often, given that we are all either sufferers or carers as well as "IiMErs", we very rarely find the time to reflect on what we have done.

Since the Conference last year we have actively participated in the Gibson Inquiry GSRME and have attended follow up meetings since. We are determined that we are going to capitalise on the positive parts of the report which, although by no means perfect, did agree with many of the important points we wanted to highlight.

Since the beginning of the year we have had meetings with the Deputy Chief Medical Officer and with Dr. Gibson, Dr. Hyde and Professor Hooper, which has led to a lot more work which should eventually lead to a very exciting development (more details below).

This year's Conference has attracted speakers from all over the world and once again we have had doctors, scientists and researchers asking us whether they could come and speak. We have a respectable number of delegates attending for both days but we really need to get the message to more professionals. If you can help in any way, for example by distributing flyers to local doctors or consultants or by mentioning the conference to your local support groups that would be much appreciated. If you would like a flyer to print please contact us at info@investinme.org; leaflets can also be downloaded from the website.

If anyone has any ideas on ways that we can get our message across, or that could help with fundraising for biomedical research, then [please contact us](#). We're sorry that, because of our IiME and personal commitments, we haven't been able to keep in touch with everyone on a personal level as much as we would like to, but we would love to hear from you. We hope that you and those that you care for are as well as possible.

Best wishes,

All at IiME

The contents of the newsletter have also changed during preparation in February. News that Professor Colin Blakemore is not going to continue as Chief Executive of the Medical Research Council altered our planned feature on the MRC. Having received a personal reply from

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Professor Blakemore to our request for a meeting we felt it warranted more campaigning to try to get the MRC to be more accountable and transparent regarding its policies and decisions.

In the wake of the Gibson Inquiry the organisations and institutions in the UK who are responsible for governance and strategy of healthcare must re-assess their policies with regard to ME.

NICE – the appalling Draft Guidelines show a breakdown in any scientific approach to treating ME/CFS.

DoH – template after template produced in response to pwme’s questions on biomedical research.

CMO – no result being effected from the CMO’s 2002 working group.

MRC – no result effected from the 2003 research advisory group. Here are comments from the MRC -

“A glance at the early records of medical research shows that organisations throughout the world frequently tended to overlook the relationship between research findings and the implementation of health policies.

Transformation of the MRC has been described as "an integral part of the national transformation of our society". The focus of all aspects of research involves human beings, and research is thus informed and guided by a culture of human rights, a vital component of the strategy of transformation. Simply expressed, these have been described as the basic components of research, always bearing in mind the needs of the greatest number [].

1. Ask the question: 'How may we improve, or how eradicate?'
2. Gather information to determine whether the question is a relevant one and to discover what is already known about the condition.
3. Formulate a plan of research to provide as many answers as can be obtained.
4. Do the research.
5. Analyse the results and findings.
6. Make the results useable as soon as possible.

Dynamically led, aware of both its importance and its accountability to the people [], the MRC faces the future with confidence, and in the keen anticipation of meeting and overcoming the challenges that will confront it.”

Fine words - unfortunately these quotes come from the Medical Research Council of South Africa! Perhaps something here for the new management at the UK MRC - and something also for NICE to consider in the coming months. We hope that the replacement for Professor Blakemore will take responsibility for altering the myopic and failed approach of the MRC in relation to ME.



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IIME Campaign - CMO and ME As a Notifiable Illness

IIME finally visited the CMO's office in Whitehall in January. Deputy Chief Medical officer Bill Kirkup hosted a representation from IIME along with Professor Malcolm Hooper, who travelled down to London for the meeting. A summary is on our ME As A Notifiable Illness page ([see here](#)). Although politely listening we aren't sure whether the CMO's office has really heard what we have been saying. Dr. Kirkup followed up with this -

"On reflection, it seems to me that the significant division of opinion that you identified between the biomedical and the psychological aspects of ME is central to the frustration that exists concerning research and treatment of this condition. In many clinical fields, for example cancer services, these approaches are regarded as complementary aspects of a holistic model – without, clearly, this in any way being seen as a commentary on the underlying nature of the condition. Of course, I am aware that the frustration exists on both sides of the divide that you identified. However, I can't help but feel that more progress would be likely if all parties did not apparently see it as such a pronounced and consequential a dichotomy."

That would be an interesting proposal to make to the psychiatric lobby who have been dominating the decisions on funding of research into ME at the UK Medical Research Council for so long.

Dr Kirkup has been invited to come to the conference to represent Sir Liam Donaldson who has declined the invitation.

The Gibson Inquiry

The Gibson Inquiry provides an opportunity for us to make progress and we feel we need to support the good recommendations made by the Inquiry. Although not perfect and with calls for sections to be rewritten it still provides a useful mechanism for attracting publicity and thus getting the essential elements of progress for ME - acceptance of correct guidelines, more education about the true features of this illness and guaranteed funding for biomedical research into ME. The inquiry is already spawning new opportunities and Dr. Gibson will be at the May conference to provide an update.



Gibson Inquiry Meeting

Sue Waddle represented IIME at the recent meeting of the Group for Scientific Research into ME (GSRME) aka the Gibson inquiry. A summary of the meeting is available [here](#).

EDM for ME

Plans are afoot for an EDM to be created by Dr. Ian Gibson's office. This would call on the government to support funding for biomedical research into ME.



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liME will be adjusting our [ME and My MP campaign](#) and hope to be able to support this EDM when it is ready and when the contents are known. More details soon.

Meeting with Dr. Ian Gibson and Dr. Byron Hyde

Some benefits from the Gibson Inquiry are evident already. We describe two in the following paragraphs.

On Tuesday 6th March Invest in ME were pleased to facilitate a meeting between Dr. Ian Gibson, Dr. Byron Hyde and Professor Malcolm Hooper, as well as two respected journalists, in London.

We hope that this will help in furthering public understanding of the issues raised by Dr. Gibson's report and will lead to tangible benefits for those affected by ME. We await one or more media pieces arising from the meeting and hope that parts of the media are now even better informed about ME.

An Opportunity for Progress

Dr. Hyde is perhaps the only physician who has been doing a total technological physical body assessment on ME and CFS patients. This has revealed an incredible amount of information on the differences between ME and CFS. Without extensive examination Dr. Hyde feels pwme will never know why they are ill and one will never get to the bottom of this group of illnesses. Employing the Nightingale M.E. Definition (see article below), some ME patients can be treated and be significantly improved and possibly be able to return to school or work.

The Gibson Inquiry has now led directly to a resolution to prepare a research proposal.

The proposal is to be prepared by Dr. Hyde, Professor Hooper and others and will involve other researchers with an aim to provide two UK centres for full body analysis of people with ME. This will involve full medical examinations being performed on people with ME using relevant equipment and techniques with the results being used to provide diagnostic evidence and techniques and further research information. The project would examine patients with myalgic encephalomyelitis and these centres would be true centres of clinical excellence. The project would not use any of the psychiatric units already set up in the UK but would be hospital/university based and would take in referrals from UK physicians. The project would involve severely affected people with ME also.

Such a proposal will not be easy to prepare; it will require consultation with many UK experts in the field; agreement of the University Hospitals to be involved and it will require defined access to highly technological tools so that patients, both adults and children can be examined within a week. Finally such a research will require a careful cost analysis, controls in some cases, and acceptance by the appropriate health committees. All this will take time.



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Invest in ME are working with Dr. Hyde and Professor Hooper and facilitating and helping with this and we hope that the eventual proposal will lead to a significant step forward in the funding of ME, the treatment of ME and the future for people with ME and their families.

This approach for making such a proposal has been evolving since the last IIME conference in 2006 and we will ask for support and participation from all ME support groups around the country and abroad.

The steps involve not just the development of the research proposal but also raising of sufficient funds in order to set up these UK centres. It already has the amazing dedication of Dr. Hyde and Professor Hooper, individuals who have not flinched in serving and helping the ME community. As Dr. Hyde points out -

"I believe that it is well worth the effort if we can even return any M.E. patients to health and productivity and to prevent future M.E. illness in children and adults....The UK will also potentially provide a spring board for European research clinics to set up similar research facilities"

"It has been a long battle but in reality, it has been Dr Ian Gibson who has opened the door to something positive happening for the chronically disabled M.E. children and adults in the UK."

Invest in ME are completely committed to this project. We believe this is an exciting opportunity which we must grasp and we will be doing whatever we have to do to try to make this opportunity a reality.

Dr. Hyde and Professor Hooper will be able to elaborate more at the Invest in ME ME/CFS Conference in London on 1st May.

The Nightingale Definition of Myalgic Encephalomyelitis

Dr. Byron Hyde has produced a new Nightingale Definition of ME for the Gibson Inquiry and for the Invest in ME ME/CFS Conference in London in May.



This can viewed [here](#).

ME Petition

Originally meant to be publicised in February we nevertheless still wish to mention the petition to the Prime Minister started by Konstanze Allsopp. Anyone registered in the UK or UK citizens living abroad can sign-up and the petition will be delivered to the Prime Minister. The deadline is 28th January 2008. Judging by the recent Pay-As-You-Drive petition, which



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received a million votes and managed to make it to the news desks across the country, it requires a great many more votes to gain the necessary publicity it deserves. It will be a difficult task (at the time of distribution this had just over 3660 signatures) so please get all friends, relatives and colleagues (and their friends, colleagues and relatives) to help this on by signing up. The petition is available [here](#).

and from Spain...

We have this story to show that the campaign for correct treatment and funding toward ME is not confined to UK or USA. Clara Valverde has sent us this report of events in Spain -

"Dear friends and colleagues far and near,

Yesterday, the Catalan Parliament accepted the Popular Legislative Initiative on Chronic Fatigue Syndrome/ME and Fibromyalgia (FM), presented by representatives from 80% of the people with CFS/ME or FM who are in associations in Catalonia.

This acceptance is the first step towards a world-first: a law that would ensure proper services for people with CFS/ME and FM and a fair treatment by medical inspectors.

Here is the news item in the Catalan Parliament's home page ([see here](#)).

No one thought that a group of ill people like us, in a not so user-friendly country would be able to pull this off. So we are all very happy and it is a big boost for the CFS/ME and FM community here.

Now that it has been accepted, the signature gathering can begin. We need 50,000 signatures and we have a team of 150 signature- collection coordinators ("fedetarios") ready to roll. Once the signatures are gathered, the law will be discussed in parliament and voted. This will probably take place in the fall.

Up to now, it has been a lot of work for us sick folks: writing the law and the document to justify each article of the law (thank you to all of you who sent me the necessary bibliography!), working with all the associations to create unity and the much needed empowerment, meeting with all political groups and sub groups (we have the support of all the political parties, except, of course, the party that runs the Health Ministry), campaigning to recruit signature coordinators, meetings with unions, women's groups others.

It has not been easy as we are presenting a proposed law that puts totally into question the government's plan to keep CFS/ME and FM solely in Primary Health Care (where most doctors do not believe these illnesses exist or do not want to work with them and are not allowed to do any relevant tests), while our law, amongst other things, demands CFS-FM units. So we have had (and continue) to deal with pressures, intimidations, etc, from government and government-related organizations. We are also having to deal with the two foundations (one run by the



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government party, the other run by businessmen) who, up to now, had managed to control and manipulate the CFS and FM associations in Catalonia and create division.

Encouraging the associations to be independent and to create unity has been hard but the most rewarding work.

The documents (the law, the justification document and other documents) are available in Catalan and some in Spanish. If anyone is interested in receiving them, let us know.

Clara Valverde

for the Promoting Commission of the CFS/ME-FM Popular Legislative Initiative, Catalonia, Spain

"

We hope to be able to welcome Clara to the ME/CFS conference in May where she may be able to give an update.

From a friend of IIME

Thanks to Gill for this, which we include not for the compliment, but for the hopes expressed which we are sure are shared by most -

"We're so aware of how the years are passing since our son and daughter were diagnosed with ME and how cruel it is for all the children with ME that they have missed out on their childhood as well as suffering enormous pain. We live for the day that someone like Jonathan Kerr will say that there is something that can be done to help, if not cure, all those who suffer from these terrible illnesses

I would like to thank everyone at Invest in ME for all your hard work in organising the Conference for us all. I fully appreciate just how much it takes to do something like this, especially as you are parents of children with ME and carers, it must be a huge amount of work and time that you all put in to it. On behalf of all the ME sufferers and carers who are going, could I say a big thank you to you all."

MRC - in Need of an Overhaul

Professor Blakemore's attitude and track record regarding ME leaves a lot to be desired and there is a bigger problem than just a failure to engage. A more systemic failure exists in the MRC where an illness affecting one in forty of the population, an illness which is recognised as the leading cause of long term absence from school, an illness which some research indicates to have been responsible for some epidemics, where such an





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illness is forced to be deprived of any sensible, organised, scientific research into its underlying causes due to denial of funding and rejection of high quality research proposals.

In IIME's response to Gibson inquiry report we stated that we would have liked the Inquiry to make one further recommendation -

..that the MRC's peer reviewing function be overhauled. If biomedical research funding is being denied for a neurological illness, yet funding is given for psychiatric research for the same illness, then the MRC peer review system is not working.

We also pondered whether this might best be accomplished by investigating the way the MRC is managed and operates. If we can discuss NICE being taken to judicial review if they insist on going ahead with their proposed guidelines on CFS/ME, without major rewrites and further analysis, then we have to ask what similar review needs to be made of the MRC?

And it is in need of a review to see the bias present. As Douglas Fraser has pointed out -

During the UK Medical Research Council's Public Consultation period for ME/ CFS in 2002-2003, and while the Public Health Research Unit (PRHU)'s Report on that Consultation was being suppressed by the MRC, the following individuals, amongst others being criticised within the PHRU document, were appointed to MRC Boards - 'acting as a core body of scientific advisors, assessing applications to the MRC..'.

- Dr T Chalder HSPHRB Representative, Department of Psychological Medicine Institute of Psychiatry London
- Dr A Cleare NMHB Representative, Department of Psychological Medicine Institute of Psychiatry London
- Professor A David NMHB Representative, Department of Psychological Medicine Institute of Psychiatry London
- Professor A E Farmer Ordinary Member, Social, Genetic & Developmental Psychiatry Institute of Psychiatry London
- Dr J R Geddes NMHB Representative, Department of Psychiatry University of Oxford
- Dr S M Lawrie NMHB Representative, Department of Psychiatry University of Edinburgh
- Dr M C Sharpe Ordinary Member, Department of Psychological Medicine University of Edinburgh
- Dr T Wykes Ordinary Member, Psychology Institute of Psychiatry
- Professor PD White, Department of Psychological Medicine at St Bartholomew's London
- Professor R P Bentall, the School of Psychological Sciences at the University of Manchester
- Professor P Cowen, the Psychopharmacology Research Unit Warneford Hospital in Oxford.

(Professors K Bhui of Barts, R Bentall, S Wessely and F Creed have all been MRC Board



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Members in the recent past).

The bias within the MRC toward psychiatric approaches to 'managing' ME is shocking in its arrogance.

["Insider trading" is a criminal offence in Finance incurring unlimited fines and custodial sentencing, and it is surely time and even more important to apply the same or similar regulations and penalties for its equivalent in the field of Medicine and Public Health.](#)

For our planned research proposal to have a reasonable chance of success we believe the way that the peer reviewing function of the MRC operates needs to be investigated, probably overhauled and made much more transparent. Professor Blakemore's departure from the MRC may aid this. His eventual rejection of our invitation to attend, or speak at, the IiME ME/CFS Conference in May was perhaps predictable. His continued refusal to engage was disappointing.

As we stated in January's newsletter the status of the MRC response to ME has been poor. The MRC's funding of current psychiatric trials - PACE and [FINE trials](#) - an investment of over £3 million - bears little resemblance to the recommendations from their briefing document of 2003. As Dr. Hyde states -

["The protocol for the PACE trial is contrary to all that modern medicine and physicians have learned since the 19th century physicians since the time and theories of William Ostler."](#)

The new MRC leadership will need to address the recommendations from the Gibson Inquiry with substance rather than obfuscation -

["Biomedical applications in respect of ME/CFS known to have been rejected](#)

[include those by Professor Jill Belch \(herself a Principal Fellow of the MRC\) and Dr Vance Spence of Dundee, as well as Dr Jonathan Kerr of St Georges, London.](#)

[It is clear that internationally there have been a number of studies, which have identified clear areas for further research. The MRC should commission British versions of this research in order to advance possible treatments.."](#) -

source GSRME report

NICE Being Investigated

While IiME now are calling for the overhaul the MRC we also welcome the fact that NICE are being investigated by the Health Select Committee. This ought to be good news when one considers the extremely poor Draft Guidelines for CFS/ME produced last year by that organisation. The Health Committee is a Select Committee of the House of Commons. It is appointed under Standing Order No.152 to examine the expenditure, administration and



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policy of the Department of Health and associated public bodies. The Committee has the power to send for persons, papers and records. The Committee has decided to undertake an inquiry into aspects of the work of the National Institute for Health and Clinical Excellence. Areas of particular interest include:

- why NICE’s decisions are increasingly being challenged;
- whether public confidence in the Institute is waning, and if so why;
- NICE’s evaluation process, and whether any particular groups are disadvantaged by the process;
- the speed of publishing guidance;
- the appeal system;
- comparison with the work of the Scottish Intercollegiate Guidelines Network (SIGN);
- the implementation of NICE guidance, both technology appraisals and clinical guidelines (which guidance is acted on, which is not and the reasons for this).

NICE have had to delay the planned publication of their Guidelines on CFS/ME until August 2007. We cannot see them being ready even by that time and feel they will have to rush through publication or risk further embarrassment.

IIME have invited both Sir Michael Rawlins (chairman of Nice) and Mr. Andrew Dillon (Chief Executive of NICE) to our conference in May. Both have declined.

Invest in ME have submitted our evidence directly to the Health Select Committee within the deadline of 23rd March and our submission calls into question NICE’s approach and performance in creation of these guidelines.

ME/CFS Conference Update



ME recently sent around a conference update to many healthcare staff around the country and beyond as well as to our regular newsletter subscribers. In this we mentioned additions to the conference line-up since our last newsletter.

Dr. Derek Pheby will be discussing epidemiology and his establishment of a national ME Research Observatory using £500,000 of lottery funding.

We also welcome Mr. Norman Lamb MP - Liberal Democrat Shadow Health Secretary. Mr Lamb has previously asked questions in parliament for Invest in ME ([see here](#)) and we welcome his involvement in the conference.





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To advertise events occurring in ME Awareness Month why not try to use GP surgeries' awareness and noticeboards? A flyer for ME Awareness Month is available from the [ME Awareness Month page](#) - the theme - *Energising ME Awareness*.

Conference Delegates

We now have ME groups attending from UK, Ireland, Norway, Sweden, Denmark, Germany, USA and maybe, as stated before, Spain. IiME would still like see as many ME support groups as possible to be represented at the conference - especially on ME Awareness & Support Day (1st May) where we can work together to create a new spirit of cooperation. Apart from the groups attending we also hope to welcome additional celebrities on the conference days. Both Dr. Gibson and Countess Mar will be at the conference and IiME have also invited several MPs and are awaiting replies.

Conference Questions Page

At the request of one of our friends and delegates to the conference we have also set up a conference question form to allow delegates to submit questions to speakers and the panels prior to the conference - [see here](#).

Conference DVD

For last year's conference we filmed the event and produced a DVD ([still available here](#)). The DVD was initially funded by IiME trustees. For this year's conference we wished to improve on last year's event and scale it up to allow an ME Awareness & Support day with a greater variety of speakers. The costs for the event are borne by the trustees again and we had not thought it possible also to fund production of a film for this year. We have been given a generous donation by IMET for the conference and, since our announcement about not filming the 2007 conference was made, several friends of IiME have also made donations. We'd like to thank all of those who donated (typical of their character they do not wish to be named) and for those other offers of help and support which we received. This means so much to us. We can't make any promise that a DVD will be produced but we are looking into it.

Use the conference links below to keep up to date with the latest information on the conference.

[Home](#)[Registration](#)[Details](#)[Venue](#)[Awareness Month](#)[Conference 2006](#)

Sponsor a Medic

Thanks to all the ME support groups who have tried to get more interest from healthcare professionals for the ME/CFS Conference in May. We are happy to report that we have received many enquiries and also actual bookings from doctors who are linking up with a local ME Support group and attending the conference at a reduced rate.

The scheme will still be running up until the conference days so please help us get as many GPs, paediatricians and other healthcare professionals to the conference in May.



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The CPD accreditation has been given to the conference (a maximum 12 points for the two days - 6 points apiece) and this can be added to the personal education plan for any healthcare professional.

More details are [here](#).

Guest Speaker - HHV6

In January came news from Stanford University of Medicine, USA, that a "preliminary study suggested there may be hope in the offing for some sufferers of chronic fatigue syndrome with a new therapy being tested by researchers at the Stanford University School of Medicine." Jose Montoya, MD, associate professor of medicine (infectious diseases), and postdoctoral scholar Andreas Kogelnik, MD, PhD, have used the drug valganciclovir - an antiviral often used in treating diseases caused by human herpes viruses - to treat a small number of CFS patients.



The researchers treated 25 patients during the last three years, 21 of whom responded with significant improvement that was sustained even after going off the medication at the end of the treatment regimen, which usually lasts six months. The first patient has now been off the drug for almost three years and has had no relapses. A paper describing the first dozen patients Montoya and Kogelnik treated with the drug was published in the December issue of Journal of Clinical Virology.

The HHV-6 Foundation was very much involved with Stanford on this project and helped fund a significant portion of the preparatory work for the clinical trial. Kristin Loomis, executive director of the HHV-6 Foundation, has said "This could be a solution for a subset of patients, but that subset could be quite large. These viruses have been suspected in CFS for decades, but researchers couldn't prove it because they are so difficult to detect in the blood. If Montoya's results are confirmed, he will have made a real breakthrough." [Click here](#) for more information on the HHV-6 Foundation.

David's Story

We include this month a story as told by a parent on a young person with ME –

From Antoinette:

"He started to deteriorate from then and ended up in hospital for a few weeks, test after test and as usual everything came back clear. He was referred to a rheumatologist and she said he was fine and to send him to school. I was dismayed by this as me and my family could all see that David was a very physically ill little boy."

Read more [here](#)



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ME Guest Groups

We are happy to publicise other groups' work where it helps. This month we have news from Louise Whitbread of the West Berkshire ME Group which provides the only support group in West Berkshire for those with ME. [Click here](#) for more information.

Our Newshound

Dr. John Greensmith is always looking for ME stories appearing in the press. Education about ME needs to be carried out on every level and at every opportunity to remove established myths and old-fashioned perceptions about the illness.

John has a contact (at [info\(at\)mefreeforall.org](mailto:info@meffreeforall.org)) for any stories appearing in the press if you wish to share.

Send us a note as well so we can keep our [Media pages](#) updated.

Irish ME/CFS Support Group

The Irish ME/CFS Support Group has recently donated 22,000 Euro to ME Research UK and 22,000 Euro to the CFS Research Foundation (CFSRF) from their research fund.



This means that the group have now given 50,000 Euro to ME Research UK and 50,000 Euro to the CFS Research Foundation in total [equivalent to approximately £67,697 or US\$132,834.75].

...and finally BLOGS and ME

Blogs are now a daily part of many people's lives. There are some useful and interesting topics and experiences on some blogs. So we thought we would devote a page to ME blogs (i.e. a Blog set up by/for a pwme or carer/parent). We started off here with a couple -simply because we saw them link to liME's website - and this may be as much a surprise to the owners as it was for us to see our link. Blogs and ME can be found at [Blogs of ME Sufferers and Carers](#).



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Send us details of your blog – we cannot take any responsibility for the content of the blogs but are willing to keep this list updated if it helps share pwme's experiences and thoughts and improve the perception of ME around the world.

The more we work together the better our chances for making real progress.

Contacts:

Inquiries to Invest in ME - info@investinme.org

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