



# Invest in ME

# NEWSLETTER



## March 2006 Newsletter

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

Invest in ME has now been operating, officially, for six months - with the web site beginning from November 2005. It's been getting ever more busier as the months have rolled on. Invest in ME have hosted talks from Malcolm Hooper; the successful Have a Cuppa For ME events were initiated and a new round is set to be announced; our London conference has been arranged and we are pleased to have announced that, since our last January newsletter, Dr. Jonathan Kerr has agreed to present at the conference and give news of his exciting work. We have also been working in the background with submissions to the Gibson Inquiry into ME, an idea for a Google Doodle and ME Awareness Month plus we have been working on one or two other ideas which are likely to be announced over the following months, if we are lucky.

Education is one of the areas we have to improve regarding ME - and education can take many forms. So we are concentrating on that topic this month. Beginning with treatments. This month we continue the expose of how severely affected people with ME are treated in the UK in 2006. Did anyone think the Meridian ITV Expose was unique?



We begin our promised section of the site looking at ME and vaccines and antibiotics. Please contact us with your thoughts and experiences.

We would also like to hear from you with any experience you have. What is your story? What are your thoughts about ME, how it is being treated? What opportunities do you feel there are in your locality for raising awareness of ME and, possibly for raising funds for biomedical research into ME? Use our [Ideas Factory](#) to work with us on new possibilities.

### IN THIS ISSUE

[Post Meridian- Bursledon House](#)

[The ME Conference Update](#)

[Events for 2006](#)

[Guest Speakers](#)

[Gibson Inquiry](#)

[ME and My MP campaign](#)

[ME Experiences](#)

[Vaccines, Antibiotics & ME](#)

[Plain Text Newsletters](#)

[Google Doodle](#)

Education + publicity = lobbying power. Lobbying power = biomedical research funding.

---

## Post-Meridian Expose



*We made it to Dawn's party yesterday,  
We have only ever met Dawn's Mum, Jo once before.*

*When we first met Jo, Dawn was being tube fed & weighed five stone.  
Someone there mentioned yesterday that she no longer has the tube & it was obvious  
she weighed more now.*

*Jo took us in to Dawn's darkened room to meet her, this gorgeous girl was lying  
perfectly still on a hospital type bed.*

*She whispered hello but couldn't raise her hand to accept a present, she whispered  
"not lying"*

*& Jo explained, "Dawn thinks people must think Jo lies about having a daughter as no  
one ever see hers".*

*That was it; the poor kid closed her eyes so we came out.*

From a friend of a family with a young girl with ME. Did anyone think that the Meridian ITV story which Invest in ME publicised in January was unique. Another shocking story. In Ceausescu's Rumania? In a poor African state? No - it's the UK in 2006 - welcome to Bursledon House!

[Read more.....](#)

## The ME CONFERENCE 2006

[There are still places left at the conference and we are particularly interested in getting healthcare professionals to come along and hear from the selection of distinguished speakers. Since the last newsletter we have now been able to add Dr. Jonathan Kerr](#) to the list of presenters. Dr. Kerr is likely to deliver some exciting information for the conference.



Once again we ask those who can to urge their GPs, or paediatricians or local PCT staff to attend and listen to the latest on clinical diagnoses, research trends and educational considerations from the people best placed to know. We have a line-up of honorary guests invited also so this will be a great chance for the ME community to get the message across. 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. More news related to the conference will be coming out in April.

---

## Events for 2006- Have a Cuppa for ME

A reminder again about our events database is available for all groups and organisations and individuals (around the world) who are interested in fund-raising for biomedical research into ME. We are introducing a new format for May 2006 to make it easier to assist in planning. 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](#). And get your tea-cups ready - another [Have a Cuppa for ME](#) campaign is underway for ME Awareness Month.



## Guest Speakers

As promised last month we have a new section set up for guest speakers. In the lead up to the ME Conference in May we hope to publish articles from all of our speakers at the conference.

This month Jane Colby and Dr. Betty Dowsett have contributed an article to Invest in ME - see [The AHA Factor and the THREE HOLY GRAILS](#).

Our Guest Speaker page is [located here](#).

---

## The Gibson Inquiry



Dr. Gibson announced the make-up of his committee for the impending review of ME in the UK. These members will begin examining the evidence submitted and we await calls for interviewing of interested parties. See [here for news on the inquiry](#).

---

## and the ME APPG....

liME wrote to the ME All Part Parliamentary Group Chairman, [Mr. Des Turner MP](#). After two reminders from our own MP this response was produced from Mr. Turner-

"I apologise for the delay in responding to your letter. I should be grateful if you could tell your constituent that the All Party Group on ME is not interested in sponsoring any particular model of ME, but is concerned to promote any relevant research into ME and to development of appropriate services. The fact there are currently no particular neurologically based interventions is a sad reflection of the fact that the knowledge base is insufficient for curative therapies to have been developed and consequently at the moment therapy tends to concentrate on, as it were, living with the disease rather than curing it.  
ME is a very difficult, complex area with a very insecure knowledge base with the consequence of the many problems which ME suffers have to bear."

As we stated earlier education is one of the areas we have to improve regarding ME!

---

## ME and My MP Campaign

An update on where we are. We have now reached over 60 UK Members of Parliament with our ME and MY MP campaign. Our aim is to get in touch with all MPs by the time of the ME Conference in London in May. Recent successes have included Scottish Nationalist MP Alex Salmond signing up to EDM 260. We have also secured support, via the Friends of IIME, for MPs Rudi Viz, Stephen Dorrell and Paul Farrelly as well as having contacted many more MPs on the subject of ME. At the time of writing the status of the EDM 260/260A in parliament stood at 223/20.

Our [campaign page](#) is updated regularly and allows one to find an MP and their status. Our template letter has been used by several friends already.

---

## ME Experiences

We are still collecting stories in the run up to ME Awareness Month. It doesn't have to be your own story if you are suffering from ME. Get someone else to write it and share their experiences of the effects of ME. The two categories - persons with ME (pwme) and carers/parents of pwme - are able to carry any story. The more we publish your experiences the more we educate. 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](#).

---

## and here is one we heard of earlier....

Thanks to Douglas for providing us with more experiences - this time from treatment at his local ME Centre (this one in West Sussex).

***"The doctor tried to extol the virtues of GET, at which point I pointed out that he was concerned about my heart rate, and yet he was asking me to increase it through exercise!"***

Read more of Douglas' story [here](#).

---

## Vaccines, Antibiotics - ME

One area of investigation has been the role of vaccines and antibiotics in the cases of people with ME. It is a subject that needs more investigation so we have started a section on this subject. This is such a wide area that we wouldn't be able to cover it all. But we have started by looking at some research from over 10 years ago - and it is interesting to see what hasn't changed. Doris Jones and Jane Colby published these articles so many years ago and we return to them as a prelude to giving more space to current research and information, as well as people's stories where links to vaccines/antibiotics are suspected.

[Read more here....](#)

And, as we go to press, news is coming in of a story from Norway linking vaccination against meningitis from the 1980s with at least 70 persons who developed ME. What is really interesting is that ME patients are being advised to put in a compensation claim whilst the Norwegian health service makes a year-long research study into this. We have translated this story and added it to the other information in this section

[Read more here....](#)

---

## Funding for Biomedical Research

People working for, and with, Invest in ME are voluntary workers. There are no salaried staff in liME. All profits from events go toward promoting and funding biomedical research into ME. We are happy to announce this month that two cheques have recently been forwarded to MERGE - one for £350 and one from Friend of liME - Anne Taylor - from a village fete event (for £1035). And, more poignantly, this from liME's regional contact Flora -

*"The mother of Samantha's godfather died in January. The family asked for donations instead of flowers and, because Dora (deceased) was very close to Samantha since birth, they donated £100 to Merge for research in memory of a lovely lady. They received a lovely letter from Merge thanking them. Yet another way, albeit a sad way, to get funding. We are grateful to Chris and Mike for kindly thinking of M.E. sufferers."*

Thanks to everyone for their support - also to those who take the time to write to us with messages - it all helps.

---

## Plain Text Newsletters

We are now also offering our newsletter as a plain text version. If you would prefer to receive our newsletter in plain text please send an email to [info@investinme.org](mailto:info@investinme.org) and entitle your email **Plaintext Newsletter**.

---

## Google Doodle

It isn't too late to add your support for a Google Doodle for ME Awareness Month. Ask Google to mark ME Awareness Day (12th May) with a special Google recognition symbol. More details [here](#).



**Contacts:**

Inquiries to Invest in ME - [info@investinme.org](mailto:info@investinme.org)

To unsubscribe from this newsletter send an email to [info@investinme.org](mailto:info@investinme.org) and entitle the email **unsubscribe**.

**RSS** link to the home page. Read more on [RSS here](#).



Invest in ME uses Paypal

Support ME Awareness - [www.investinme.org](http://www.investinme.org)

---

**Contacts:**

Inquiries to Invest in ME - [info@investinme.org](mailto:info@investinme.org)

Please support us - support biomedical research.

Support ME Awareness - <http://www.investinme.org/>

---

[Go to Newsletter Home Page](#)

## ***Invest in ME***

**UK Registered Charity Nr. 1114035**

**PO BOX 561,  
Eastleigh SO50 0GQ  
UK**

