

Invest in ME

**A Charity Campaigning for
People with Myalgic
Encephalomyelitis (ME) and
Their Families**

Annual Review 2009

Overview of the Charity

Objectives

The main objectives of Invest in ME have been to educate the public, media and healthcare organisations and staff about ME/CFS and campaign and lobby for a national strategy of co-ordinated, biomedical research to provide treatments and a cure for this illness.

Our objectives are now developing to play an active role in funding biomedical research into ME – either by applying for grants directly for research projects or by facilitating the funding of research projects.

The work performed by invest in ME is entirely voluntary, with no paid staff or large administrative costs. Income that we receive from donations or sales of educational material is used to pay for the production of our international biomedical research conferences, educational DVDs, books, booklets, web site and in funding new ideas to campaign for proper treatment for people with ME/CFS and their families.

Invest in ME is a charity which tries to provide as much information as possible for free or at cost-price for people with ME and their families.

Better education regarding ME is of prime importance for Invest in ME. Our belief has always been that this is the only way that misinformation and ignorance about ME can be overcome so that correct decisions or actions may be taken by healthcare professionals, government organisations, the media and people with ME and their families. We believe this policy has been successful and is continuing to have beneficial effects for people with ME.

In this way we can progress the likelihood of funding biomedical research which is the only sure way to find appropriate treatments and cures for the various sub groups of ME.

We endeavour to provide services, products and information for free or as near to cost price as possible.

The organisation of annual International ME Conferences in London attracts doctors, scientists, researchers, sufferers and carers from around the world.



The production of educational material (DVDs, booklets and guidelines) related to ME is performed to enable healthcare staff, patients, politicians, the media and the public to have better and more accurate knowledge about this disease.

The charity has produced a book about families' and patients' experiences of ME and how their lives have been affected.

Numerous research activities to support TV, radio and newspaper coverage of ME were performed and IiME contributed to the consultation and review of the NICE Guidelines for ME/CFS.

Initiation of awareness and fund-raising activities regarding ME were performed. The charity has begun a Biomedical Research Fund which we hope will allow donations to research projects to be made. We intend to apply for grants to assist researchers in their biomedical research toward ME.

2008 - 2009

liME organised and hosted the fourth annual Invest in ME International ME/CFS conferences in London. The focus of the conference for 2009 was **Severe ME**, an attempt to raise more awareness of severe ME - a group of patients who are not represented in research trials and misunderstood by healthcare services. Many believe that studying severe ME will yield treatments and cures for this illness and have repercussions for other services including management of ME.



Figure 1 Professor Jonathan Brostoff - Chair for the 2009 Invest in ME conference

The conference was another great success and progressed the education and awareness of the severely affected ME patients, with speakers and delegates attending from four continents and from 14 countries.

The conferences brought together some of the foremost experts on ME/CFS from around the world and representatives from ME/CFS patient groups from all over the UK and Europe and from as far afield as USA, Canada, South Korea, Australia and New Zealand.

Both the Chief Medical Officer and the UK Medical Research Council were represented at the conference as were several charities and organisations from across the UK and Europe.

The conference was again CPD accredited.

Widespread publicity was achieved and has led to further areas of cooperation between researchers and ME support groups.

The conference again showed clear, undisputable evidence of the organic nature of the illness but also, more importantly, showed that treatments were available for some sub groups of ME and that some patients were being treated effectively to allow them to lead normal lives.

Prior to the conference Invest in ME had arranged for the famous American journalist, Hillary Johnson, to visit London and give a pre-conference presentation on the evening before the conference to an audience of researchers, clinicians, patients and media people. Hillary's presentation concerned the USA CDC's influence on ME research throughout the world. The interest in Hillary Johnson was tremendous as her seminal novel, *Osler's Web*, described the politics and the intrigue behind the workings on the Centres for Disease Control in USA.

The presentation was impressive and shocking, telling some of the inside story of how ME has been manipulated by a government agency. This has so many parallels to the concerted campaign to misinform which has occurred in the UK over the years.

liME again attempted to make the conference available to as many patients and patient groups as possible by reducing the registration price for people with ME and their carers. This again meant that the registration price was heavily subsidised.

liME also continued its policy of allowing reduced registration prices for any doctor/clinician who registered via a contact with a local ME support group. In

this way we attempted to encourage cooperation between physicians and patients at a local level.

Important new research was presented at the conference and a great deal of media interest was generated by the conference.



The DVDs produced from the conference have been distributed around the world and sold in over 20 countries. Together with the educational DVDs from previous IiME conferences these continue to form an invaluable source of educational material for doctors, healthcare personnel and researchers and also for ME patients and ME support groups.

The DVDs have been used by healthcare staff for CPD points accrual where they could not attend the conference.

IiME took part in lobbying of MPs and also facilitated participation for feedback to both the NICE Guidelines on ME/CFS and campaigned for better understanding of the issues relating to ME.

IiME have facilitated meetings between ME clinicians and researchers and the media and MPs.

IiME chair the European ME Alliance – an organisation which brings together ME support organisations from across Europe to promote better understanding of ME and to be able to campaign and lobby across Europe.



In the year we have published another edition of the Journal of IiME – a blend of research, science, politics, advocacy and real stories of the suffering caused by ME to patients and families.

Invest in ME published the Journal of IiME [[click here](#)] at the conference and abstracts of the conference presenters' presentations are included therein.

The Journal is available for free to anyone who can download it from our web site and we have made hard copies available to others who have no access to the internet as well as including it in every conference delegate's information pack.

Due to funding constraints we have not been able to make this available in hard copy format to as many as we would wish. We hope to change that in the future.

The charity marketed a Quotable Quotes booklet which has been created by distinguished advocates for ME.

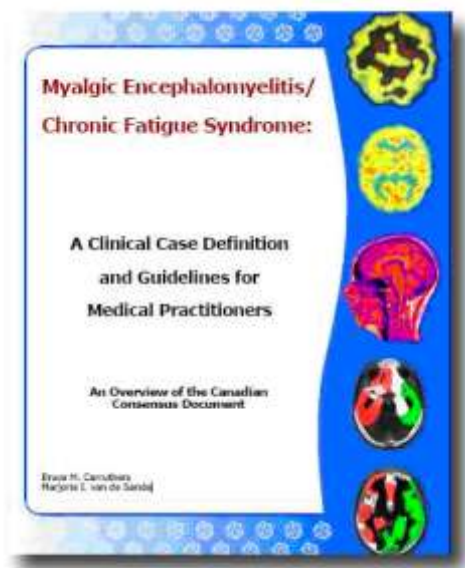
We have also published and distributed the unique new book on ME, Lost Voices, which was compiled by Natalie Boulton and highlights the situation of those severely affected by ME and their families. This book has been ordered by patients, support groups, healthcare staff and researchers in

twenty countries. It has also been ordered for inclusion in the syllabus by Chicago University, USA.



Invest in ME took on the cost of production of this book in order to distribute as widely as we could to all sections of society so that all can be aware of this national and international tragedy which has been allowed to continue for generations. We have been aided donations for this. We feel this unique book is an indispensable supplement for understanding the effects of this disease.

IiME continue to be the official UK official distributors and supplier for the Canadian Guidelines document for diagnosis of ME.



During the year Invest in ME also established a Biomedical Research Fund to allow the charity to assist in funding biomedical research into ME. We hope this will, over time, allow new research to be funded in the UK.

Invest in ME publish a free monthly newsletter to several thousand subscribers.



Invest in ME have submitted responses to the published 5-year plan for CFS (ME) from the USA Centres for Disease Control. The charity also submitted responses to the UK All Party Parliamentary Group on ME.

In order to engage with the healthcare services the charity wrote an open letter to the Chief Medical Officer of England ([click here](#)) arguing the case for greater involvement by the CMO in the way ME was being perceived and treated in the UK. We followed later with an appeal to the Prime Minister.

We would like to thank our loyal supporters for their support and donations which have enabled us to continue to perform our work.





Invest in ME Statement of Finances October 2008 – September 2009

Income	Unrestricted Funds	Restricted Funds	Total Funds	Last year
Conferences and Associated DVDs	18,722	-	18,722	12,732
Donations, legacies and grants	20,212	-	20,212	8,972
Brochures, Books & Guidelines	6,773	-	6,773	694
Bank Interest	3	-	3	28
Gift Aid	1,534	-	1,534	-
Fund-raising for BRF	-	905	-	-
Total Income	47,244	905	48,149	22,426

Expenses	Unrestricted Funds	Restricted Funds	Total Funds	Last year
Conferences and Associated DVDs	31,075	-	31,075	20,318
Printing of Brochures, Books & Guidelines	8,404	-	8,404	-
Meetings, Travel	1,008	-	1,008	463
Postage, Packaging, Stationery	4,538	-	4,538	1,011
Insurance	465	-	465	486
Web Services, Governance	153	-	153	82
Advertising in Interaction magazine	299	-	299	-
Total Expenses	45,492	-	45,492	22,397

Income	Unrestricted Funds	Restricted Funds	Total Funds	Last year
<i>Net of receipts/(payments)</i>	1,302	905	2,207	29
Cash funds last year end	270	-	270	241
<i>Cash funds this year end</i>	1,572	905	2,477	270