

INVEST in ME

ANNUAL REVIEW 2007

*A Charity Campaigning for Benefits for
People with ME/CFS and Their
Families*

www.investinme.org



Invest in ME Annual Review



Kathleen McCall

In September 2007 invest in ME celebrated its second year as an organisation which campaigns for better education and more funding of biomedical research into **Myalgic Encephalomyelitis** (ME/CFS) in order to enable benefits to be gained for patients, their carers and families.

Invest in ME (IIME) was set up by parents of children with ME/CFS, or sufferers of ME/CFS and was initially created due to the lack of progress being made in raising awareness of the seriousness of this illness. The main objectives of Invest in ME are 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.

The work performed by invest in ME is entirely voluntary. We have no chief executives or other paid staff. Any income we receive from donations or sales of educational material is used to pay for the production of our conferences, DVDs, booklets and web site and in funding new ideas to campaign for proper treatment for people with ME/CFS and their families.



*Dr. Ian Gibson MP – speaking at the
Invest in ME International ME/CFS
Conference*



Our view is that any charity which is concerned with ME/CFS should have as its objectives the facilitation of proper diagnosis, treatment and eventually a cure for this disabling illness. We feel this is best achieved by improved education about the condition.

During our first accounts period we have organised and hosted two successful international conferences in London – the first lasting one day and the second spanning two days – both attempts to provide more patient focus and more biomedical research. We have been happy with the results of these conferences.

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.

The breadth of knowledge, science and experience regarding ME/CFS, as discussed and presented at the conferences, was not only impressive but also exciting. There are real grounds for hope that progress is being made on finding possible treatments/cure for ME/CFS.

We are glad to see that the many contacts which were established at the conferences have continued. To see renowned experts on ME/CFS discussing with each other and forming or re-enforcing collaborative efforts was reward enough for hosting the conference. To turn into reality our efforts to form a world alliance of campaigning ME/CFS Support organisations was also justification for the conferences.

The presentations from our distinguished speakers displayed an amazing amount of knowledge regarding the organic nature of myalgic encephalomyelitis.

The many emails and letters from delegates which we received after the conferences endorse the view that these conferences enabled far more lasting and productive working relationships than could otherwise be achieved. Many people commented on how energized they felt after the

conferences and this has led to far more awareness of the need for change and new initiatives being planned. Interestingly, we also had similar comments from healthcare staff and from researchers who attended the conferences. Both conferences were CPD accredited and were attended by delegates and researchers from a dozen countries – testifying to the desire for knowledge about the illness as well as concern that more needs to be done.



Mr. Norman Lamb MP – LibDem Shadow Minister for Health – at the 2007 IIME International ME/CFS Conference

Invest in ME made the decisions to fund the DVD of the conferences in order that we had a permanent record of the events of that day and of the impressive science which exists already.

The DVDs of the conferences, which were created for the express purposes of allowing as many people as possible to see and learn from the experts at the conference even if they were not able to attend due to their illness, have been distributed in twenty countries and testify to the need for education about ME/CFS. They are an educational tool for physicians to learn about ME/CFS.

We have been very glad and appreciative for the support we have received from many individuals and organisations throughout the UK, and abroad. Without this support we could not have performed the conferences, the DVD or many other things. We have gained new and continuing working relationships with other groups in the UK and abroad.

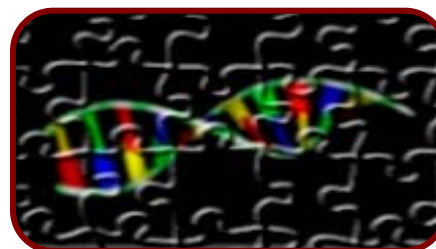
For both conferences Invest in ME set the ticket prices for people with ME/CFS and their carers as low as we possibly could as we believe that it is vitally important that patients and patient groups are as well educated about this illness as we demand from healthcare staff. Our aim is always to perform our work for free or at cost-price, wherever possible.

We believe that everyone who attended our conferences left not only with an enhanced knowledge gained from the conference but also with renewed hope for the future treatment and possible cure for myalgic encephalomyelitis. As Professor Malcolm Hooper commented in his introduction to the Issue 1 of the Journal of IIME - "*achievements, hope, and future actions were brought together in this conference*".

We also worked with ITV Meridian and Norway's Puls programme to allow their excellent reporting on severe ME/CFS in the UK and Norway to be seen. These programs were made available for our 2006 conference DVD set and form a powerful and realistic statement on how disabling ME/CFS can be to patients and their families.

During the period we have contributed to the review of the NICE Guidelines (both the draft version and the official version). We have found both documents unsatisfactory due to the large omissions and the unscientific emphasis on psychiatric paradigms to manage/treat ME/CFS. Bearing in mind the amount of evidence which exists of the organic nature of ME/CFS it was surprising to see no mention of this evidence. Invest in ME produced a 52-page response to the NICE guidelines (following our 38000 word response to the draft guidelines) and these were added to our web site where many other research and informational documents are stored.

In order to engage pro-actively with officials and organisations Invest in ME have been in contact with government and healthcare officials in attempts to open up a wider debate on how ME/CFS is being treated in the UK.



We visited the CMO's office to meet with Dr. Bill Kirkup, Deputy CMO, where we requested that ME/CFS be treated as a notifiable illness in schools. Unfortunately, the CMO has not followed up on his report on ME/CFS from 2002 and, like the subsequent Gibson Inquiry (for which IIME also provided evidence), the opportunity is being missed to realise the creation of a proper strategy for dealing with ME/CFS.

Invest in ME have written to past and current ministers at the Department of Health and to the

Medical Research Council in order to discuss the overwhelming evidence now available to support funding of more biomedical research. The chief executive of the MRC contributed an article for our Journal for the 2007 conference.



We hope we have effected some change in views and were glad to welcome the MRC at one of our conferences. Our discussions with the MRC will continue.

We have written to many MPs on the subject of ME/CFS and have been pleased to see questions asked in the House of Commons following this.

liME started the Have a Cuppa for ME idea where local groups and individuals could raise money for biomedical research into ME/CFS by organizing tea or coffee mornings. Many thousands of pounds has been raised by groups across the country and in Ireland due to this scheme and our thanks go to all of those involved.



liME created the Journal of liME – a combination of research, science, news, information, facts, politics, real life experiences and other articles relating to myalgic encephalomyelitis in order to raise awareness of ME/CFS – real experiences coupled with actual evidence and ongoing research. Our first version of the Journal appeared in the delegates' conference pack at our International conference in London in May 2007 and the second issue appeared in November 2007.

From the Journal of liME was born the Quotable Quotes booklet – a useful selection of referenced information regarding ME/CFS. This booklet is selling around the world and again endorses the view that better education is a major requirement in order to change policies regarding ME/CFS.

Invest in ME also took over distribution of the Canadian Guidelines in the UK on a not-for-profit basis. The guidelines are now a basic requirement for any service model being developed for diagnosis, management and treatment of ME/CFS.

The Canadian Guidelines, the 2007 and 2006 conference DVD sets, the Journal of liME and the Quotable Quotes on ME booklet, provide a useful range of educational material for healthcare staff, politicians, media and, of course, ME patient groups and patients and their carers.

Dr Byron Hyde has also produced extremely useful documents on ME/CFS and we have had the privilege of hosting Dr. Hyde's booklets on our web site, in addition to his presentations at both of our conferences.



Dr. Byron Hyde – speaking at the Invest in ME International ME/CFS Conference 2007

The Invest in ME web site (www.investinme.org) also receives up to 60,000 visits per month and is another resource available to inform public, media and healthcare professionals about ME/CFS.

We have translated into English the Norwegian documents describing the exciting news of the Norwegian government's intentions to treat ME/CFS more seriously and with a more strategic approach, including creation of centres of excellence for ME/CFS. We feel our efforts have helped in publicising to the world the wonderful work being performed by the Norwegian ME Association – something also recognised at our 2007 conference when our Norwegian colleagues received a great ovation.

liME has also been involved in supplying research information for the BBC Radio 4 Programme "You and Yours" which recently aired a series of programs on ME/CFS.

Accounts

Our accounts for the period have been provided below and show a deficit for the period, whilst retaining a small credit in our account overall. This reflects the fact that we were granted charity status during our preparations for the first ME/CFS conference. It also reflects the fact that all of our work is performed for free with no salaries paid and the only charges made are for items where we attempt to recoup the cost of production. The

largest proportion of the accounts relates to our annual conferences which we feel have been a vital element in our work to benefit all ME/CFS sufferers and their families.

Our intention is to use whatever finances we have to improve the education and awareness of people involved in dealing with ME/CFS and to treat this with the urgency it deserves.

Lives are being lost due to this illness - a fact to which too many ministers, politicians and organisations still remain indifferent. The only way to cure ME/CFS will be via a national strategy of biomedical research which includes adequate funding. We believe everyone needs to share the sense of urgency which ought to be applied to an illness which is destroying the lives of young and old alike.

Invest in ME will continue to operate in this way. Our aim is to help make a difference to people with ME/CFS and their families and to obtain wider recognition of the disabling nature of this condition for all who are affected by it.

Looking Forward

As with many illnesses for which insufficient funding is available it is the patients and carers who often learn the most about the illness, out of necessity. It is the patients, families and carers who are forced into lobbying for proper attention. Invest in ME was created through such a state of affairs.

Looking ahead our future objectives remain -

- Education
- Campaigning for biomedical research
- Supporting research efforts of others
- Lobbying

We are determined that what happened to Sophia Mirza, who died, "... as a result of acute renal failure due to dehydration arising as a result of Chronic Fatigue Syndrome (ME/CFS)" must never be allowed to happen again.

Our aim, where possible, will be to continue to provide information and educational material either for free or at cost price - the London conferences being an example of this where people with ME/CFS and/or their carers could attend for a basic price which covered just food and refreshments.

We hope to continue our annual biomedical research conferences and attract new and interesting speakers. The conferences were meant to supply a platform for researchers, healthcare

staff and patients and patient groups to listen to the latest research on ME/CFS and enable opportunities to discuss and plan ways of diagnosing, managing, treating and hopefully curing this illness.

Our planned conference for 2008 continues this theme with an exciting line-up of world-renowned researchers and physicians. As we plan for the May 2008 conference we look forward to working together with those interested in campaigning for funding of biomedical research into ME/CFS - the only sure way to provide a cure for this neurological illness.

We hope to publish our Journal more frequently and will continue to offer our newsletter -both available for free from our web site. We hope the Journal of IIME will also continue to assist in this area by providing a platform, as does the IIME conference, for biomedical researchers and clinicians to provide details of their research and



Representatives from the Norwegian ME Association at the London conference

work.

We look forward to strengthening our connections with UK and international groups who share the same objectives and to continuing to engage ministers and organisations responsible for the health of citizens in this country.

We hope we have helped make a difference but the future must lie in working together to improve the chances of proper treatment and a cure being found for ME/CFS and Invest in ME welcomes the chance to cooperate with organisations and individuals who are prepared to look for new and better ways of making a real difference in the perception, diagnosis, treatment and awareness of ME/CFS.

Kathleen McCall

Chairman Invest in ME
December 2007



Invest in ME Statement of Finances May 2006 – September 2007
(as provided to the Charities Commission)

Income	Unrestricted Funds	Restricted Funds	Total Funds	Last year
Conferences and Associated DVDs	26,690	-	26,690	-
Donations, legacies and grants	3,487	-	3,487	-
Brochures & Guidelines	1,175	-	1,175	-
Bank Interest	18	-	18	-
Total Income	31,370	-	31,370	-

Expenses	Unrestricted Funds	Restricted Funds	Total Funds	Last year
Conferences and Associated DVDs	35,231	-	35,231	-
Brochures & Guidelines	1,997	-	1,997	-
Donations	200	-	200	-
Postage, Packaging, Stationery & Collection boxes	1,754	-	1,754	-
Insurance	738	-	738	-
Web Services, Governance	199	-	199	-
Bank charges	23	-	23	-
Total Expenses	40,142	-	40,142	-

Income	Unrestricted Funds	Restricted Funds	Total Funds	Last year
<i>Net of receipts/(payments)</i>	-8,772	-	- 8,772	-
Transfers between funds	9,000	-9,000	-	-
Cash funds last year end	9,013	-	9,013	-
<i>Cash funds this year end</i>	9,241	9,000	241	-