INVEST IN ME
ACCOUNTS REVIEW
2010-2011

Annual Review 2011

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

> **"how grateful we are for the work you're doing for all of us" – *E.***

ACHIEVEMENTS and PERFORMANCE

Invest in ME has continued its policies of promoting the need for biomedical research into myalgic encephalomyelitis (ME), improving the knowledge and education of healthcare professionals regarding ME and encouraging patients to take more responsibility for enabling and promoting proper research into this disease.

Invest in ME have continued to promote the proposal for biomedical research to be based at a research and examination facility in the Norwich Research Park in Norfolk. The Research Park includes multiple institutes and companies, including the University of East Anglia, Institute of Food Research and the Norfolk and Norwich University hospital. Our proposal envisages performing translational biomedical research into ME by researchers at the university using patient cohorts which has been diagnosed by an experienced clinician using accurate diagnostic guidelines.

Invest in ME has been actively lobbying with MPs in Norfolk and the media to effect change in the treatment and perception of ME. We have been in discussions with university, hospital and PCT to enable this proposal to become a reality.

In this we have been joined and supported with a new and visionary fundraising initiative – Let's Do It For ME – which began toward the end of this financial period and continues. By the financial end period almost £10000 had been raised toward biomedical research into ME.

Invest in ME continue to promote our model and discussions are continuing. We view this proposal as one of the best ways forward for securing proper research and treatments for people with ME in the UK and Europe.

IiME organised and hosted the sixth annual Invest in ME International ME/CFS conference in London. This had the theme of "***The Way Forward for ME – A Case for Clinical Trials***" to reflect the need for clinical trials of treatments for ME which could make a difference to the lives of patients.

The 6th IiME conference (IIMEC6) was again CPD accredited and was a platform for biomedical research. This 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 over 15 countries.

The IiME conferences allow researchers to discuss and collaborate and patient groups and patients to network and foster cooperation. The widespread publicity which is achieved by the conference serves as a beacon for hope that proper science will prevail and that a change in government strategy will eventually be made to allow proper information, correct education and sufficient funding for biomedical research into ME.

As always IiME maintained its policy of making the conference accessible 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.

IiME 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.
IiME also self-funded the places of a number of other researchers and healthcare staff in order to raise more awareness of the biomedical research and of the treatments which were available for ME or which are being developed and trialed.

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

Invest in ME organised six events over the conference period. Prior to the conference Invest in ME had arranged for a visit to parliament for a number of our conference presenters. Invest in ME coordinated with the All Party Parliamentary Group for ME (APPG) chairman for five of our presenters to address the APPG (this followed the APPG having invited Invest in ME to be an observer at APPG meetings). This was a valuable meeting as it allowed the APPG chair and other MPs to hear directly from some of the most experienced ME researchers and clinicians in the world.

Invest in ME also organised a “Corridor Conference” – a unique meeting of researchers from around the world with the intention of establishing collaboration and cooperation and provide a chance to discuss possible future research strategies for ME. This proved extremely useful and we hope that this will lead on to further discussions and meetings.

On the evening before the conference Invest in ME arranged and hosted the Science, Politics and ME pre-conference presentation dinner. Our speakers were Hillary Johnson, the acclaimed US journalist, and Dr Ian Gibson, former MP and Dean of the School of Biological Sciences at the University of East Anglia. Their fascinating presentations showed different aspects of the way that science and politics get mixed up when discussing ME – on both sides of the Atlantic.

IiME continued to chair the European ME Alliance and also chaired the annual general meeting of the European ME Alliance – a group of patient organisations and charities from eleven European countries 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.

Invest in ME are one of the founding members of EMEA.

IiME helped in formulating media publicity campaigns to request the health ministers from European countries could join us in London for the IIMEC5 conference and discuss with researchers.

We also oversaw the introduction of Switzerland to the Alliance and have been working on inclusion of other members within Europe.

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 are able to be used by healthcare staff for accrual of CPD points when they could not attend the conference.

Invest in ME produced another DVD of the conference and included the Science, Politics and ME evening presentations.

In our newsletters and on our web site we published articles by researchers, clinicians and patient advocates which showed the issues with poor research and the need to raise awareness of proper science which was benefiting people with ME and their families.

Invest in ME wrote several times to the BBC and our comments have been included in some BBC reports regarding ME.

Invest in ME contacted the Chief Medical Officer and Department of Health to clarify the situation with the ban on blood donations by people with ME – pointing out the inconsistencies with the approaches towards blood and organ donations by patients.

The charity also commented on the PACE Trial – a misuse of scarce funding which left patients and physicians no wiser regarding how to treat ME patients.

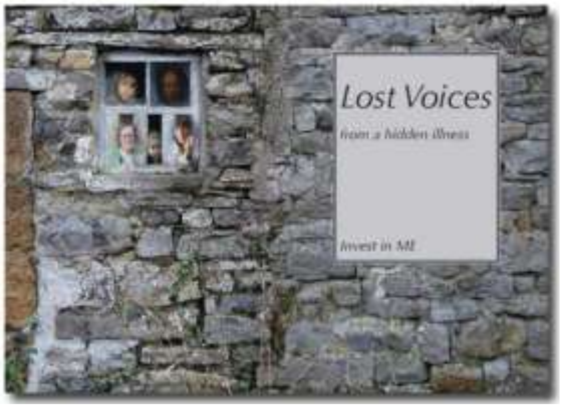
We followed up by submitting comments to the Lancet and inviting the Lancet editor to our annual conference.

Invest in ME made an official complaint to the Press Complaints Commission after a series of unsubstantiated and biased articles appeared in major newspapers in a seemingly coordinated media attack on sick and vulnerable patients. Although the PCC did not rule in the charity’s favour the bias and inaccurate reporting in this misleading articles and the unprofessional and flawed editorial control were clearly shown by Invest in ME to be present in the media – something which would again be symptomatic of poor journalism shown later by the Leveson Inquiry.

In the year IiME 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. We would like to publish more editions each year but the constraints of funding and time has meant we have not been able to. It remains our objective to publish the Journal of IiME four times per year.

Invest in ME continue to market the Quotable Quotes booklet which has been created by distinguished advocates for ME.

Invest in ME continued to distribute copies of the unique new book on ME, Lost Voices. This book is undoubtedly the best tool available to show the real situation for those affected by ME and for their families. This book has been ordered by patients, support groups, healthcare staff and researchers in over twenty countries.



IiME continue to be the UK supplier for the Canadian Guidelines – the current document for correct diagnosis of ME.

The Invest in ME Biomedical Research Fund was eventually switched to fund our proposal for an examination and research facility for ME in Norwich.

A full page ad was taken out in the London Business Matters magazine – with Invest in ME being the Charity of the Month for May 2011.

The charity’s Burst Our Bubble campaign for ME Awareness focused on the lack of attention being given to ME and highlighted how ME patients were isolated from the rest of society – forced into a bubble of apathy and neglect.

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

Invest in ME continue to have no membership fee and we attempt to perform all of our work for free or as near to cost price as possible.

Further Financial Review Details

The charity has benefited again from a small but loyal group of supporters who have kindly shown wonderful support and assisted us.

The IIMEC6 conference was also facilitated by the wonderful and generous support again from the Irish ME Trust of Ireland, whose support has again helped Invest in ME to organise the conference.

Several fund-raising initiatives have been organised by friends and supporters.

The trustees continue to supplement the funds in the charity with personal donations. The Trustees feel that it is important to try to make the conferences and the DVDs and other educational material within the reach of patients and their families, many of whom are unable to work due to the effects of this devastating neurological disease. The charity continues to feel that better education of healthcare staff is the key to improving conditions for people with ME and their families.
As stated IiME aim to provide all our work for free or at cost price.

We continue to be an independent charity whose focus is on better education, better awareness and more biomedical research for myalgic encephalomyelitis.

We hope to continue to fund research and provide a means for patient groups to raise more awareness of this disease – ME – and so enable a more rapid and morally just resolution to be created by provision of treatments and cures from proper science.

Invest in ME Statement of Finances October 2010 – September 2011

Income	**Unrestricted Funds**	**Restricted Funds**	**Total Funds**	**Last year**
Conferences and Associated DVDs	**17,595**	**-**	**17,595**	**14,332**
Donations, legacies and grants	**21,671**	**9,890**	**31,561**	**30,510**
Brochures, Books & Guidelines	**2,910**	**-**	**2,910**	**3,344**
Bank Interest	**1**	**-**	**1**	**1**
Gift Aid	**1,231**	**-**	**1,231**	**195**
Fund-raising Charity Activities	**429**	**-**	**429**	**1,263**
Misc.	**30**	**-**	**30**	**15**
Total Income	**43,866**	**9,890**	**53,736**	**49,660**
Expenses	**Unrestricted Funds**	**Restricted Funds**	**Total Funds**	**Last year**
Conferences and Associated DVDs	**37,712**	**-**	**37,712**	**28,611**
Printing of Brochures, Books & Guidelines	**2,688**	**-**	**2,688**	**9,456**
Donations	**-**	**-**	**-**	**4,114**
Meetings, Travel	**695**	**-**	**695**	**628**
Postage, Packaging, Stationery	**1,704**	**-**	**1,704**	**2,852**
Insurance	**489**	**-**	**489**	**458**
Governance, Web Services	**585**	**-**	**585**	**749**
Advertising	**-**	**-**	**-**	**-**
Fundraising Products/Equipment	**379**	**-**	**379**	**-**
Total Expenses	**44,521**	**-**	**44,521**	**46,868**