Invest in ME

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

Annual Review 2010

www.investinme.org

Charity Nr. 1114035

Overview of the Charity

Objectives

Since Invest in ME (IiME) was formed a prime objective has been to educate the public, media and healthcare organisations and staff about myalgic encephalomyelitis (ME or ME/CFS) – a basis upon which to campaign and lobby for a national strategy of co-ordinated, biomedical research to provide treatments and a cure for this illness.

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.

IiME works to build relationships nationally and internationally with other ME Charities and organisations and individuals who promote similar aims. In particular IiME have continued to chair the European ME Alliance, a working group of ME support organisations across Europe. We also have cultivated links to many organisations, researchers, healthcare staff and media persons.

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. We recognise that patients and their families are already severely affected by the problems which accompany this illness – from possible misdiagnosis, to lack of knowledge by healthcare providers, to unsympathetic and ignorance exhibited by social services, educational and healthcare departments, and including the financial impact due to loss of income.

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

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

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.

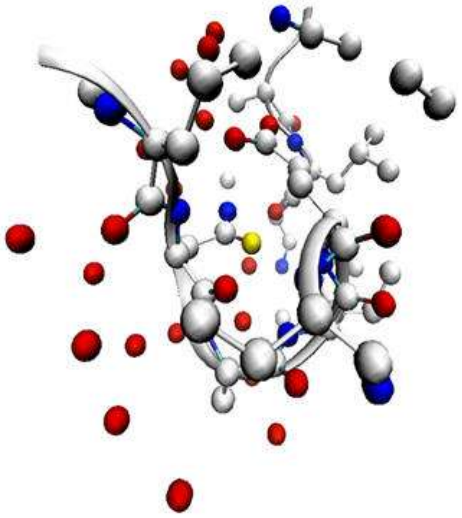
The charity has facilitated the production of a book about families' and patients' experiences of ME and how their lives have been affected.

The charity has provided numerous research activities to support TV, radio and newspaper coverage of ME and IiME contributed to the consultation and review of the NICE Guidelines for ME/CFS.

IiME also initiated multiple awareness and fund-raising activities regarding ME. The charity has continued to use its Biomedical Research Fund to allow the funding of research projects to be made. We intend to apply for grants to assist researchers in their biomedical research toward ME.

2009 - 2010

For many years Invest in ME have been more and more aware of the need for patients to take responsibility for enabling and initiating proper research in to myalgic encephalomyelitis. This is seen as required due to the continuing failure of the government to adequately fund biomedical research into ME – leading subsequently to lack of any real potential to progress the discovery of treatments and cures for ME



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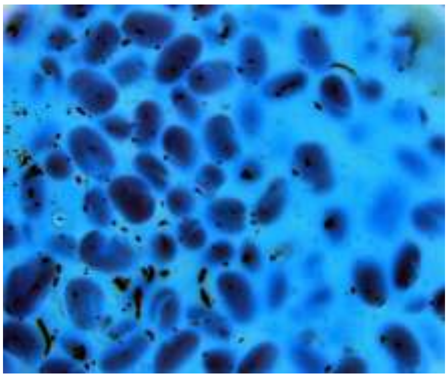
Invest in ME have attempted to do this by forming a proposal for biomedical research to be based at a research and examination facility in the Norwich Research Park in Norfolk. The research park includes multiple institutes and companies, including the University of East Anglia, Institute of Food Research and the Norfolk and Norwich University Hospital.

Our proposal envisages performing translational biomedical research into ME by researchers at the university using a patient cohort which has been diagnosed by an experienced clinician using accurate and modern diagnostic guidelines.

Invest in ME formed a steering group to initiate this proposal and entered discussions with the university and hospital and with a renowned clinician. IiME have been in discussions with Norfolk PCT also and have secured a promise from the PCT to fund the examinations. These discussions are continuing and we have had a good deal of success. We shall continue to promote our proposal as one of the best ways forward for securing proper research and treatments for people with ME in the UK and Europe.



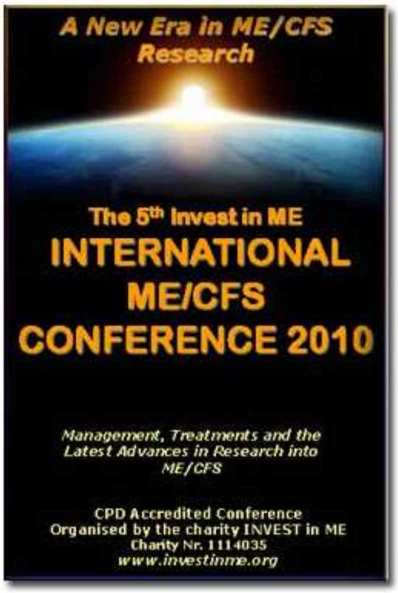
During this financial year Invest in ME decided to initiate an idea to perform biomedical research with the Whittemore-Peterson Institute of Nevada, USA, to determine the prevalence of XMRV in a UK ME patient cohort.

In discussions with WPI Invest in ME asked what could be done to counter the negative and biased coverage which was being given to the WPI's research. The idea of a UK study was born and IiME agreed to help fund this research. This study led to numerous presentations and a future paper being prepared by WPI.

IiME organised and hosted the fifth annual Invest in ME International ME/CFS conference in London. This had the theme of "***A New Era in ME/CFS Research***" to reflect the new awareness and acceptance that only biomedical research will allow treatments and cures to be found for ME.

The 5th IiME conference (IIMEC5) 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.



A New Era in ME/CFS Research

The 5th Invest in ME

INTERNATIONAL ME/CFS CONFERENCE 2010

Management, Treatments and the Latest Advances in Research into ME/CFS

CPD Accredited Conference
Organised by the charity INVEST in ME
Charity Nr. 1114035
www.investinme.org

The 2010 Conference DVD

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 – mainly thanks to the trustees of IiME.

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 trialled.

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

Prior to the conference Invest in ME had arranged for a round-table discussion between researchers to be made and filmed for the conference DVD. This meeting proved to be extremely informative and has helped many patients and healthcare staff to be aware of how biomedical research is progressing and the issues which researchers are facing.

The **American Journal of Biochemistry and Biotechnology** invited Invest in ME to submit papers from the conference for publication by the Journal. This resulted in an important paper by Professor Leonard Jason being published.

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.

IiME took part in lobbying of MPs and raising awareness. We continued our "ME and My MP" campaign by writing to politicians, CMO and to government ministers.

We questioned the Department of Health and the Chief Medical Officer regarding the need to prohibit blood donations from people with ME – the first UK charity to do so. We also wrote to the General Medical Council in support of a GP who was unfairly disciplined

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.

All articles are available in our news archive sections on our web site - http://www.investinme.org/Index%20News%20Archive.htm

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

Invest in ME continued its criticism of the NICE Guidelines for ME/CFS which we view as lacking in any real usefulness for physicians or patients. We also continued to criticise the PACE trials as flawed science and a huge waste of public money – money which could have been far better utilised if allocated for biomedical research into ME.

IiME continued to 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. 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 Alliance published several press releases to request a European ban on donation of blood by ME patients in order to protect blood supplies from potential contamination by an infectious agent. The Alliance petitioned European ministers of health and the European Commission – with IiME playing a major role in helping draft letters.

Invest in ME also invited European health ministers to the 5th IiME conference in London.

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 [http://www.investinme.org/InfoCentre%20-%20Journal%20of%20IiME.htm]. 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.

THE CLOTHWORKERS' COMPANY

We have been aided in this work by a grant from the **Clothworkers' Foundation** for new IT equipment.

This grant has allowed modern equipment to be used to produce better documents, improved web site functions and editing capabilities for our DVDs. We are now able to perform even more work ourselves thus saving time and money which can be directed toward biomedical research and activities to raise awareness of ME. It has also allowed us to produce informational packs which can be sent to libraries, hospitals GP surgeries and to patients around the country.

Invest in ME continue to market the Quotable Quotes booklet which has been created by distinguished advocates for ME and which lists comments by known advocates of ME being a behavioural illness.

Invest in ME continued to distribute copies of the unique 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 twenty countries. It was also ordered for inclusion in the syllabus by De Paul University in Chicago, USA.

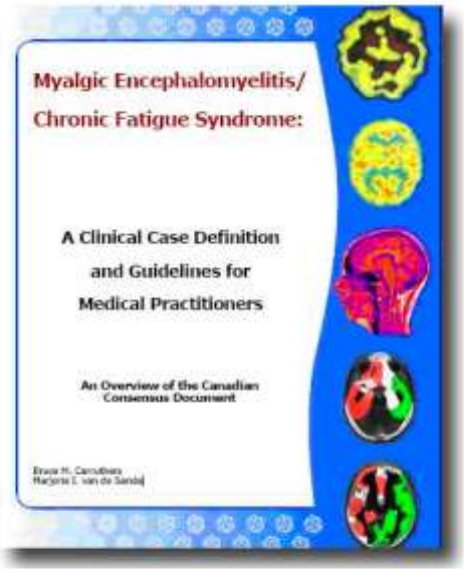
The charity was fortunate to receive a grant from the **Foyle Foundation** which enabled IiME to produce a second edition which included a new international story.

FOYLE FOUNDATION

This generous grant by the Foyle Foundation has enabled us to continue to raise awareness by allowing people who were otherwise unknowledgeable about ME to be made aware of the true situation and about the appalling conditions which people with ME and their families have to endure.

Thanks to this grant and to funds raised by supporters we were also able to send a copy of Lost Voices to each of the medical libraries in the UK.

IiME continue to be the UK supplier for the Canadian Guidelines – the most current document for correct diagnosis of ME. The Canadian Guidelines were once described by the National Institute for Clinical Excellence (NICE) as the ,most stringent available for ME and the charity continues to promote their usage as it provides the best aid possible for doctors to diagnose accurately this disease.



Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome:

A Clinical Case Definition and Guidelines for Medical Practitioners

An Overview of the Canadian Consensus Document

The Invest in ME Biomedical Research Fund has been used to fund the WPI studies mentioned earlier. We maintain an ambition to raise more for the Fund and allow additional biomedical research to be formed.

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.

The charity has benefited again from a small but loyal group of supporters who have kindly shown wonderful support and assisted us. We would like to thank our loyal supporters for their support and donations which have enabled us to continue to perform our work.

The IIMEC5 conference was also facilitated by the wonderful and generous support again from the Alison Hunter Memorial Foundation of Australia and the Irish ME Trust of Ireland. These two organisations represent the best in the International ME community and their support has again helped Invest in ME to organise a conference and associated DVD.

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 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 based on proper science.

Invest in ME Statement of Finances October 2009 – September 2010

Income	**Unrestricted Funds**	**Restricted Funds**	**Total Funds**	**Last year**
Conferences and Associated DVDs	**14,332**	**-**	**14,332**	**18,722**
Donations, legacies and grants	**30,510**	**-**	**30,510**	**20,212**
Brochures, Books & Guidelines	**3,344**	**-**	**3,344**	**6,773**
Bank Interest	**1**	**-**	**1**	**3**
Gift Aid	**195**	**-**	**1,534**	**1,534**
Fund-raising for BRF	**-**	**1,263**	**1,263**	**905**
Misc.	**15**	**-**	**15**	**-**
Total Income	**48,397**	**1,263**	**49,660**	**48,149**
Expenses	**Unrestricted Funds**	**Restricted Funds**	**Total Funds**	**Last year**
Conferences and Associated DVDs	**28,611**	**-**	**28,611**	**31,075**
Printing of Brochures, Books & Guidelines	**9,456**	**-**	**9,456**	**8,404**
Donations	**1,946**	**2,168**	**4,114**	**-**
Meetings, Travel	**628**	**-**	**628**	**1008**
Postage, Packaging, Stationery	**2,852**	**-**	**2,852**	**4,538**
Insurance	**458**	**-**	**458**	**465**
Governance, Web Services	**749**	**-**	**749**	**153**
Advertising	**-**	**-**	**-**	**299**
Asset and investment purchases, etc	**3,023**	**-**	**3,023**	**-**
Total Expenses	**47,723**	**2,168**	**49,891**	**45,942**

Income	**Unrestricted Funds**	**Restricted Funds**	**Total Funds**	**Last year**
Net of receipts/(payments)	**674**	**905**	**231**	**2,207**
Cash funds last year end	**1,572**	**905**	**2,477**	**270**
Cash funds this year end	**2,246**	**-**	**2,246**	**2,477**