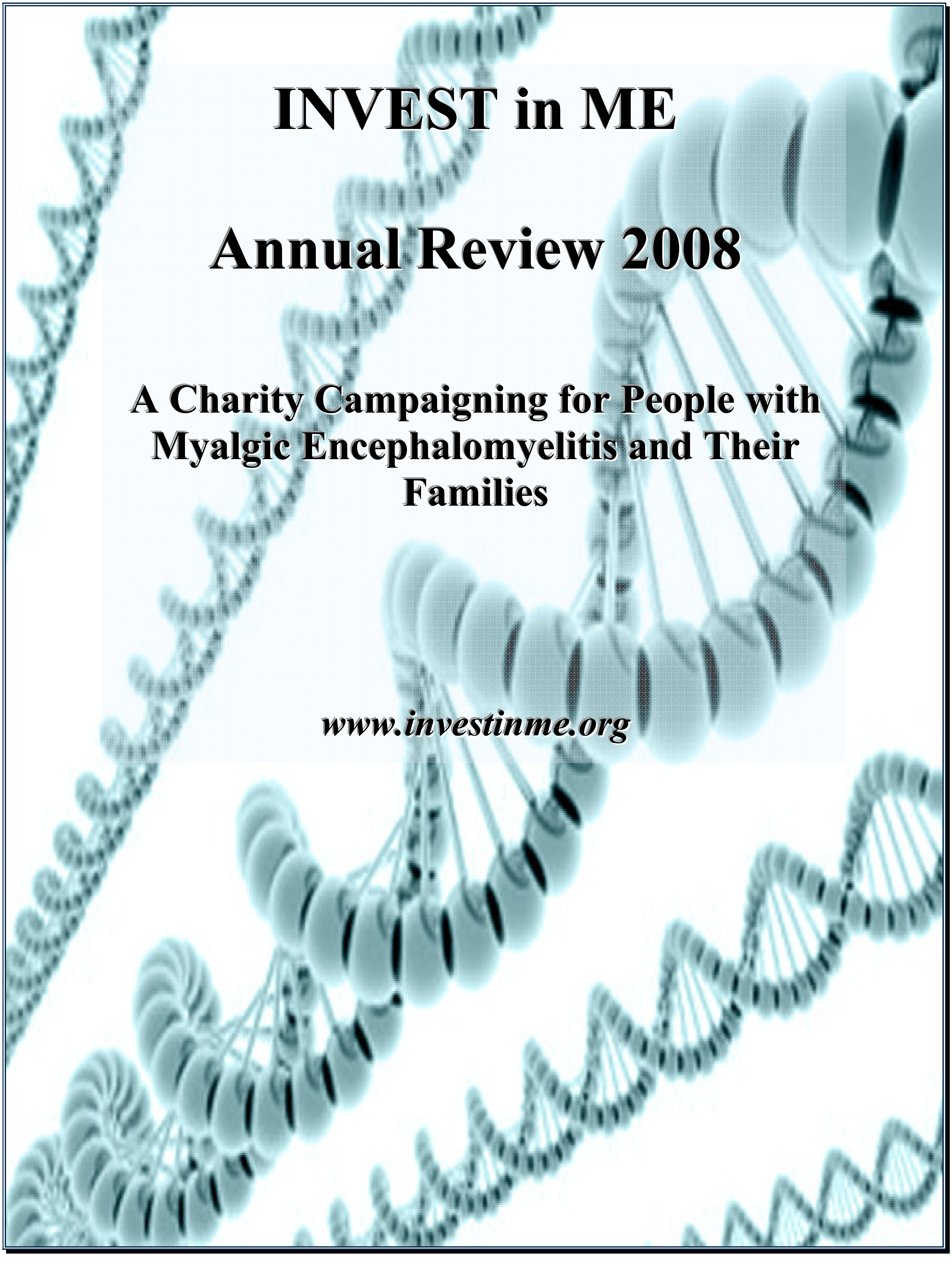


INVEST in ME

Annual Review 2008

A Charity Campaigning for People with Myalgic Encephalomyelitis and Their Families

www.investinme.org

Invest in ME
Annual Review

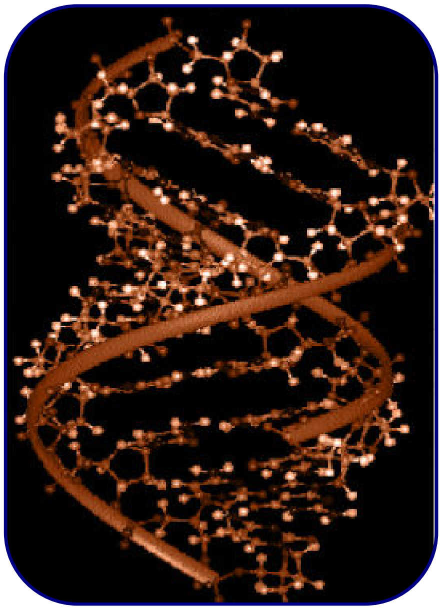
Kathleen McCall

Looking back

Invest in ME are now in the fourth year of existence as an organization and are celebrating our third year as a UK charity.
Invest in ME campaigns for better education about myalgic encephalomyelitis (ME or ME/CFS) and works towards establishing a coordinated, funded national strategy for performing biomedical research into ME.

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 continue in the spirit in which were created – with all our work being voluntary and without any 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 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.



Our aim is to improve the knowledge and education surrounding ME so that healthcare professionals, government organisations, the media and people with ME and their families can better understand the illness and avoid being affected by misinformation and ignorance, which are still major problems amongst many areas of society. 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.

Invest in ME is a charity which tries to provide as much information as possible for free or at cost-

The presenters at the 3rd International ME/CFS Conference 2008 in Westminster, London price for people with ME and their families.

The Invest in ME International ME/CFS Conferences

During the accounts period ending September 2008 Invest in ME have continued to organise and host the International ME/CFS Conference – a platform for the latest biomedical research into ME which attracts researchers, clinicians and patient groups from around the world.

The international conference is a CPD- accredited event held in London which has become the premiere ME conference in the UK and Europe.

The 3rd Invest in ME International ME/CFS Conference of 2008 broke new ground by looking specifically at the various Sub Groups of ME and at the treatments available. The conference 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.

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 2008 conference brought together researchers, healthcare staff, patient groups and media from thirteen different countries - a testament to the success of the conference and to the need for

Conference Quotes

"We would like to convey our sincerest gratitude to Invest in ME for organising such a fantastic conference. Without people like you, we and many, many others would be lost. Thank you for caring and for wanting to make a difference in the lives of suffering people. You all deserve a medal!"

"The conference was great and it was really a good feeling to be among others who are working for the same aim. It was also great to see and to hear all these medical researchers who explain at least a good part of this illness and to have the occasion to speak to them."

"To all at IiME - Thank you so much for another fantastic conference. It was a joy and a relief to be able to listen to people who are starting to understand the biomedical complexities of this condition. It goes without saying that your hard work is greatly appreciated."

"What can I say? Wow and thank you yet again! A super conference and well worth the effort to get there. Brilliant speakers, great programme."

"Opened new lines for looking at literature references, in order to enhance research on CFS/ME."

"Fantastic! The best ME conference I have been to and thanks to Invest in ME for making the price so realistic for people with ME. I learned so much from this day."

"I enjoyed it all - especially being given ideas that may be able to use in practice and to be given ideas for where to look for future research to keep updated in CFS/ME practice. I have been able to gain a better understanding of CFS/ME and diagnostic criteria and changes to it. Very useful to be aware of research that is going on and how practices differ in UK to USA. I hope to see if any can be put into practice within our CFS/ME service."

"It is encouraging to see how much research is taking place and how many great medical professionals are making towards diagnosis and more recognition. Very good organisation of the event, wide variety of speakers and materials."

access to correct education about the illness.

An increased number of professional healthcare staff also attended the conference demonstrating the continuing interest and expectations of the IiME conferences.

The emails and letters we received after the conference from delegates continued to demonstrate to us that our efforts to improve education are working with patient groups and healthcare professionals stating they had learnt so much from these events. The additional, new data being presented by our speakers also provided information on treatments which are available now for some sub groups of ME.

Much of this research has not been available by other means to UK audiences.

Our conference review is available here - **http://tinyurl.com/5mu4ja**.

The incredible amount of biomedical research now taking place, despite being mainly privately funded, is showing very promising progress in developing treatments for this debilitating neurological illness – something giving hope to people with ME and their families.

The 4-disc 2008 Conference DVD

During the financial year we continued to offer our 2006 and 2007 conference DVDs as educational aids for physicians, healthcare staff and patients/patient groups.

These were supplemented by the presentations from the 2008 conference.

This DVD has been sold in twenty different countries and has been ordered by researchers, politicians, doctors, healthcare staff, journalists, film companies and ME support groups and patients.

The DVDs are professionally authored material representing the full contents of the International ME/CFS conference as well as containing additional information to improve education about ME/CFS.

The networking allowed by the Invest in ME conferences has allowed new initiatives to be taken by many groups and individuals.

This has led to the creation of the European ME Alliance (EMEA) – a group of national organisations from around Europe who have come together to create more awareness of ME and coordinate joint efforts to build an infrastructure which will serve European patients better.

Invest in ME are a founder member of the EMEA and we look forward to collaborating with our European colleagues in the year ahead.

Web Site

The Invest in ME web site (www.investinme.org) continues to provide useful and current information to all interested in learning about the illness. During the year the site has experienced well over ½ million hits and continues to grow and is another resource available to inform public, media and healthcare professionals about ME/CFS.

Newsletter

Our free e-newsletter is distributed around the world every month.

INVEST in ME
Nr. 08/01 January 2008
NEWSLETTER

This enables patients, patient groups and healthcare staff to be appraised of events concerning ME which affect not only those in the UK but also those in other countries. For many this provides the only access to news, research and information on ME.

Education and Information on ME
As part of our educational offerings we continue to market the An Overview of the Canadian Consensus Document – A Clinical Case definition and Guidelines for Medical Practitioners. These are peer-reviewed guidelines for clinicians and are an essential part of any healthcare organisation to correctly diagnose ME. Misdiagnosis is still a major problem for people with ME and many patients are left without correct diagnosis. The Canadian Guidelines provide a means for clinicians to more accurately diagnose ME.

Invest in ME are the official distributors for the Overview of the Canadian Guidelines in the UK.

Journal of IiME
IiME continue to produce Journal of IiME – 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.

The Journal has published articles from leading ME researchers from around the world as well as introducing other areas of research which might have implications for ME.

We have translated from Norwegian into English more documents from the wonderful work of our European ME Alliance colleagues at the Norwegian ME Association. These documents describe 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.
With major articles from distinguished physicians, researchers and advocates the Journal is unique. In the last financial year we published two versions of the Journal of IiME.
We also included a conference brochure with the Journal in the delegates' pack at the 2008 international conference.

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. 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.

Research
Invest in ME have tried to be a proactive partner with healthcare services and government bodies in order to rectify the incorrect perceptions of ME. Our educational material provides up to date knowledge about the illness but we have also been working with other groups and organisations in other countries as international cooperation is one of the keys to combating ignorance.

Mrs Annette Whittemore and Dr. Daniel Peterson – founders of the Whittemore-Peterson institute for Neuro-Immune Diseases, Nevada, USA

We have made a permanent slot in the international conference for the Whittemore-Peterson Institute for Neuro immune Diseases (WPI) in Nevada, USA, to allow their latest research and strategies to be presented. Our 2008 conference introduced the WPI's Research Director presenting the latest biomedical research and our 2009 conference will see the President of the WPI making the keynote speech and the co-founder and research director both returning to provide the latest research.

We believe the WPI is the model of a research establishment for all governments to consider creating. It has the best of ideas and biomedical research being planned and performed and is, in our opinion, the way forward in order to find diagnostic tests, treatments and cures for the various sub groups of ME.

Invest in ME secured invitations from WPI to the Secretary of State for Health, the Chief Medical Officer and the head of the Medical Research Council to visit the WPI in Nevada and see for themselves how this unique centre is being developed to find treatments and a cure for ME and other neurological illnesses.

These officials have also been invited to the official opening of the WPI in 2010.

MRC, DoH and CMO

In order to be a proactive organisation for improvement of education in healthcare services Invest in ME invited the Department of Health, the Medical Research Council (MRC) and the Chief Medical officer (CMO) to attend the conference and we have offered to work with those departments to improve education regarding ME/CFS.

MRC Medical Research Council

Invest in ME have continued to write to the current ministers at the Department of Health and to the Medical Research Council in order to bring about a change in policy toward ME.

Invest in ME believe we have had some success in helping to change the emphasis by MRC.
The MRC contributed another article for our Journal for the 2008 conference.

Having invited the MRC and CMO to the conference we hope some change is on the way in their policy though we also warn of the flawed view of allowing MRC policy to be unduly influenced by powerful vested interests which seek to avoid funding of pure biomedical research into ME.

IiME have continued to lobby politicians and PCT staff in order to raise correct awareness of the issues relating to ME and have been pleased to see questions asked in the House of Commons following this.

By engaging with staff at all levels we hope to influence decision-making by those entrusted with the responsibility for healthcare provision.

Media

Invest in ME have contributed to media programmes regarding ME.

BBC NEWS

We have been in contact with the BBC, ITV, Norwegian and Swedish television and the national newspapers in UK and Europe and provided valuable research information to some television and radio programmes in order for them to make more informed comment on ME.

We also have begun working with independent film companies in producing documentaries on ME.
We hope these will provide results in the next year.

Invest in ME also established a Facebook site.

facebook

The facebook group is a very popular way of making contact, particularly for the younger generation, and could be a life line for some ME sufferers.

Legislation

Invest in ME became stakeholders to the NICE guidelines for ME/CFS.

Having contributed to the review process we have maintained our opposition to the NICE guidelines as being unfit for any national approach to treating ME patients and unusable for healthcare services who wish to provide appropriate treatments for the illness.

NHS
National Institute for
Health and Clinical Excellence

During the year Invest in ME has assisted some patients by taking up their cases with local services, PCTs, hospitals and members of parliament. We have helped some patients gain access to proper medical attention after their own healthcare practitioners failed to provide referrals to consultants.

Although not having an official help line we have taken on the responsibility for assisting some ME patients to gain proper and just services when other organisations have failed them and when they have been refused appropriate attention from their local GP.

The plight of severely affected ME patients is a national scandal and Invest in ME continue to demand that wholesale changes be made in the way that ME patients are discriminated against by many areas of society.

Many may have now forgotten Nikki McNougher. Nikki chose an assisted suicide rather than continue with the pain she was experiencing from ME.

Her husband, Peter, contacted the chairman of IiME in May, shortly after our conference, to explain the story of his wife and her wish to offer her tissues/organs for medical research into ME.

As we stated in our September 2008 newsletter if the story of Sophia Mirza should have been a watershed in the inhumane treatment of people with ME - and should have been the turning point when ministers, medical officers, healthcare staff and organisations representing people with ME began to act responsibly - then this story should actually force the government to act.

It is ironic that people with ME such as Nikki can get help to die yet the UK government provides no help for people like her to live.

Invest in ME
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Accounts

Whilst Invest in ME does not demand subscriptions from anyone we do, nevertheless, still have considerable costs in providing the international conference, the DVD, the web site and the books and booklets as well as distributing correct information about ME around the country and helping with families and patients who are having trouble in getting appropriate treatment from healthcare services.

The trustees have made substantial donations in order to enable these crucial events, products and assistance to continue and we have been helped by a small but loyal band of supporters who have helped us financially as well as by giving encouragement to enable us to continue. We would like to thank everyone who has helped us during the year.

Our accounts summary for the period is provided below and show a small credit retained in our account overall.

As we have no paid staff and our overheads are

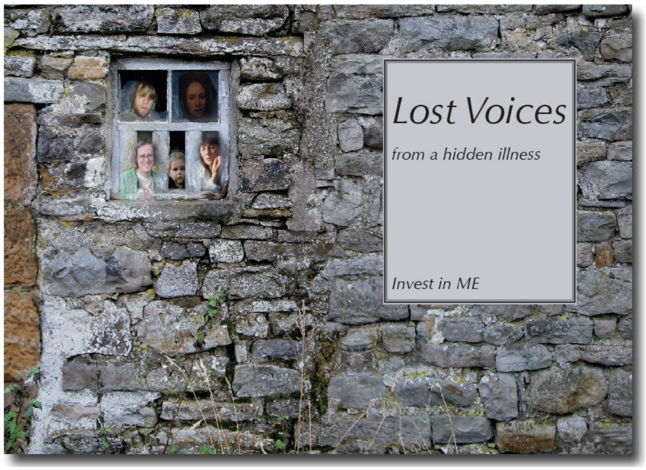
small we are able to maintain an objective to use our funds where they are best required and which benefit people with ME or the ME research community.
Invest in ME will continue to use available funds for work on our objectives and will, where possible, do this with an immediacy that we feel is necessary.
Our feeling is that action is required now and we have no intention of scarce funds sitting idly in a bank account while people are suffering from this illness.

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.

We aim to use our financial resources to continue to provide world-class conferences and first-class educational material for all interested in ME.

Looking Forward
Invest in ME look forward to the next year with new approaches to improving the perception of ME in order that necessary funding can be gained to support biomedical research into this illness.

We will publish a new book, Lost Voices, which will provide an opportunity for people with ME, who are usually invisible and unheard, to speak for themselves, so that their situation can be seen and understood more clearly.



The book will enable show the evidence of the devastating impact this physical disease has on individuals and their carers and families and bring to more public notice the plight of ME sufferers.

Invest in ME will take on the cost of production of this book in order to be able to distribute as widely as we can to sections of society so that all can be aware of this national and international tragedy which has been allowed to continue for generations.

The work that Invest in ME perform is voluntary but, through necessity, we have more passion to achieve progress for people with ME and their families than ministers, politicians or some healthcare departments. Our knowledge of the subject is crucial and education is the key for progress.

There is far too little attention being paid to the plight of people with ME by the government and the Chief Medical Officer and by PCTs around the country.

The reality is that we have to compete for funding with other worthy causes.
What we should not have to do is to compete for proper perception of the illness.

Our education will resolve this.

Looking ahead our future objectives remain -

- Education of healthcare service providers
- Campaigning for biomedical research
- Supporting research efforts
- Lobbying for better awareness of ME
- To campaign for correct and appropriate ME/CFS services for all people with ME/CFS
- Raising more funds to aid in or efforts to increase biomedical research

Our Methods of achieving these objectives are by –

- International conferences
- European cooperation
- Educational material being made available
- Establishing a biomedical research fund for ME
- Completing other projects in the pipeline for improving awareness of ME

Our aim, where possible, will be to continue to provide information and educational material either

for free or at cost price - the CPD-accredited London conferences being an example of this where people with ME/CFS and/or their carers being given the opportunity to attend at prices they can afford.
The Invest in ME international conferences provide a platform for researchers, healthcare staff and patients and patient groups to become aware of the latest research on ME/CFS and will lead to more opportunities to expedite better diagnosis, management, treatments and hopefully curies for this illness.
Our planned conference for 2009 continues this theme with an exciting line-up of world-renowned researchers and physicians.

Invest in ME welcomes the chance to cooperate with organisations and individuals who have the same objectives and 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. We will continue to campaign for funding of biomedical research into ME/CFS – the only sure way to provide a cure for this neurological illness. Through cooperation and partnership with European and international groups and researchers who share the same objectives we hope to help move things on quickly.

Our hope has been to increase the frequency and improve the distribution of our Journal as we feel this is a valuable aid in increasing education. We will continue to provide our newsletter. Both the Journal and the newsletter will remain free from our web site for everyone.

By providing an annual conference, a research Journal twice a year and a monthly newsletter we feel we are providing a platform for biomedical researchers and clinicians and patients to provide details of their research and work and experiences.

We shall continue to engage ministers and organisations responsible for the health of people with ME in this country.
We hope to be able to continue to improve education about ME and will be looking to strengthen our workings and cooperation with our European partners in the European ME Alliance.

Invest in ME aim to establish a biomedical research fund which will attract funding for research, education and services for researchers and people with ME. We believe it is a fact that only through private funding of ME research will the breakthroughs occur which can see improvements in diagnosis, treatments and in producing a cure for ME in our lifetimes.
As such we will become more vigorous in our grant-applications for more funding and we shall work with our European colleagues to effect this.

Support ME Awareness – Invest in ME

Our slogan is Support ME Awareness – Invest in ME. We will continue to promote better awareness of ME – through education, more funding for biomedical research and the best treatment for people with ME and their families. For those wishing to help Invest in ME in its work we welcome support, both financial and in resource to help us promote improved education and better awareness regarding ME.

Kathleen McCall
Chairman Invest in ME
February 2009

Invest in ME

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Invest in ME Statement of Finances October 2007 – September 2008
(*as provided to the Charities Commission*)

Income	Unrestricted Funds	Restricted Funds	Total Funds	Last year
Conferences and Associated DVDs	**12,732**	**-**	**12,732**	**26,690**
Donations, legacies and grants	**8,972**	**-**	**8,972**	**3,487**
Brochures & Guidelines	**694**	**-**	**694**	**1,175**
Bank Interest	**28**	**-**	**28**	**18**
Total Income	**22,426**	**-**	**22,426**	**31,370**

Expenses	Unrestricted Funds	Restricted Funds	Total Funds	Last year
Conferences and Associated DVDs	**20,318**	**-**	**20,318**	**35,231**
Brochures & Guidelines	**-**	**-**	**-**	**1,997**
Donations	**-**	**-**	**-**	**200**
Meetings, Travel	**463**	**-**	**463**	**-**
Postage, Packaging, Stationery	**1,011**	**-**	**1,011**	**1,754**
Insurance	**486**	**-**	**486**	**738**
Web Services, Governance	**82**	**-**	**82**	**199**
Bank charges	**37**	**-**	**37**	**23**
Total Expenses	**22,397**	**-**	**22,397**	**40,142**

Income	Unrestricted Funds	Restricted Funds	Total Funds	Last year
Net of receipts/(payments)	**29**	**-**	**29**	**-8,772**
Transfers between funds	**0**	**-**	**0**	**9,000**
Cash funds last year end	**241**	**-**	**241**	**9,013**
Cash funds this year end	**270**	**-**	**270**	**9,241**