

INVEST IN ME RESEARCH

England & Wales · Charity number 1153730

Details

Other names	IIME
Status	Registered
Legal form	CIO
Registered	2013-09-09
Register	View on the Charity Commission register

Contact

Address	16 Cheriton Road Eastleigh Hampshire SO50 5BA
Phone	02380643736
Email	info@investinme.org
Website	www.investinme.org

Activities

Objects: TO PROMOTE AND PROTECT THE PHYSICAL AND MENTAL HEALTH OF SUFFERERS OF MYALGIC ENCEPHALOMYELITIS THROUGH THE PROVISION OF SUPPORT, EDUCATION AND PRACTICAL ADVICE.TO ADVANCE THE EDUCATION OF THE GENERAL PUBLIC IN ALL AREAS RELATING TO MYALGIC ENCEPHALOMYELITIS.TO PROMOTE RESEARCH INTO CAUSES AND TREATMENT OF MYALGIC ENCEPHALOMYELITIS AND TO PUBLISH THE USEFUL RESULTS OF SUCH RESEARCH FOR THE PUBLIC BENEFIT

Activities: IIMER PROMOTES BIOMEDICAL RESEARCH/EDUCATION/AWARENESS OF MYALGIC ENCEPHALOMYELITIS (ME). WE ORGANISE ANNUAL INTERNATIONAL ME CONFERENCES/RESEARCH COLLOQUIUMS; MARKET & PUBLISH EDUCATIONAL MATERIAL ON ME (DVDS, BROCHURES, GUIDELINES & JOURNALS); PUBLISH A FREE NEWSLETTER; INITIATED NATIONAL/INTERNATIONAL CAMPAIGNS FOR CROWDFUNDING/AWARENESS FOR ME; FUND BIOMEDICAL RESEARCH INTO ME.

Classification

- **How:** Makes Grants To Organisations, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body, Other Charitable Activities
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities, Other Charities Or Voluntary Bodies, The General Public/mankind

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-09-30	£112,945	£131,965	-	-
2023-09-30	£65,248	£95,918	-	-
2022-09-30	£363,811	£21,228	-	-
2021-09-30	£161,990	£208,529	-	-
2020-09-30	£61,026	£231,956	-	-

Trustees

Name	Role	Appointed
KATHLEEN ELIZABETH MCCALL	Chair	2013-08-20
Joyce Wood		2014-09-11
Richard Simpson		2013-08-20

INVEST IN ME RESEARCH

England & Wales - Charity number 1153730

Accounts



Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	01	10	2023		30	09	2024

Section A Reference and administration details

Charity name

INVEST in ME RESEARCH

Other names charity is known by

IiMER InMER IiME RESIME Invest in ME

Registered charity number (if any)

11153730

Charity's principal address

PO Box 561
 Eastleigh
 Hampshire
Postcode **SO50 0GQ**

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Kathleen McCall	Chairman		
2	Richard Simpson	Trustee		
3	Joyce Wood	Trustee		
4				
5				
6				
7				
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Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

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Section B Structure, governance and management

Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	CIO Foundation Model
How the charity is constituted (eg. trust, association, company)	CHARITABLE INCORPORATED ORGANISATION
Trustee selection methods (eg. appointed by, elected by)	Appointed by Existing Trustees

Additional governance issues (Optional information)

<p>You may choose to include additional information, where relevant, about:</p> <ul style="list-style-type: none"> • policies and procedures adopted for the induction and training of trustees; • the charity's organisational structure and any wider network with which the charity works; • relationship with any related parties; • trustees' consideration of major risks and the system and procedures to manage them. 	<p>Invest in ME Research (IiMER) works to build relationships nationally and internationally with other organisations who promote similar aims.</p> <p>The charity is a founding member and chair for sixteen years of the European ME Alliance, a collaboration of national patient organisations and charities across Europe.</p> <p>The charity also has cultivated links to many organisations, researchers, clinicians and healthcare staff and initiated, and continues to support European groups of researchers, clinicians and young researchers who will work together.</p> <p>Our objectives are to facilitate high-quality biomedical research into ME with international collaboration and development of a centre of excellence for ME that will serve UK and Europe.</p>
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Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

<p>To promote and protect the well-being of sufferers of ME. To advance the education of the public in relation to ME. To promote research into causes and treatment of ME.</p>

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

The main activities are–

Organisation of annual public International ME Conferences that attract doctors, scientists, researchers, patients and carers from around the world to collaborate and share knowledge about ME.

Organisation of international research colloquiums to encourage new collaborative and cooperative possibilities for research into ME.

Creation and development of network of young researchers for ME.

Foundation and support of a collaborative European ME Research Group network for researchers to come together.

Foundation and support of a collaborative European ME Clinicians Council network for European clinicians to come together to build knowledge and expertise around ME.

Production of educational material (videos, booklets, journals and guidelines) related to ME.

Finding, facilitating and funding of biomedical research into ME.

Continuing development of the Centre of Excellence for ME model that the charity has proposed and championed since 2011.

Initiation of awareness and fund-raising activities regarding ME.

Maintenance of web sites for the charity, and European ME organisations containing educational information regarding ME and our initiatives and conferences

Creation and administering of webinars to enhance education of the public and to disseminate information around Europe regarding ME.

Advocacy work to help patients in need. Participation in DHSC working group to develop policies for ME.

Distribution of regular newsletters to patient groups, patients, healthcare staff, media, politicians and general public regarding ME.

Board member of the European ME Alliance and participating in European collaborative projects regarding awareness of ME.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

The trustees and volunteers perform all of the charity's work for free.

The charity does not have any salaried staff.

The charity endeavours to provide services, products and information for free or as near to cost price as possible, to avoid ME patients having to bear additional burdens around costs.

The charity has a Biomedical Research Fund that allows grants for research projects to be made in an attempt to initiate more biomedical research into Myalgic Encephalomyelitis.

The charity has a peer review process for examining applications for grants.

The charity attempts to initiate more biomedical research into Myalgic Encephalomyelitis with an emphasis on international collaboration.

The charity has published our policy on grant making on our web site.

We are continuing to support our proposal to develop a UK/European Centre of Excellence for ME that will include examinations and research facility into ME and would perform biomedical research into the disease and allow proper examinations and diagnosis for ME patients.

We have initiated several major research studies for ME in UK.

Section D

Achievements and performance

Summary of the main achievements of the charity during the year

Invest in ME Research

Period: October 2023 – September 2024

Invest in ME Research (IIMER) is a small charity with a clear strategy of research, education, and advocacy, always aiming to look at the bigger picture and facilitate meaningful change through innovation, ideas, and determination.

The charity remains dedicated to improving the lives of people with myalgic encephalomyelitis (ME), as well as their families and carers. We continue to challenge misconceptions and raise awareness of ME in scientific, media, and public circles, striving to advance understanding of the disease and to overcome flawed and outdated beliefs.

No salaries have ever been paid by IIMER; all work is performed by volunteers. There is no intention to employ an expensive CEO or support staff, as our dedicated volunteers bring the necessary skills, knowledge, and commitment to our objectives. This ensures that the maximum possible funding is directed toward our essential aims: biomedical research into ME and events that facilitate education and collaboration.

The charity continues to campaign for, fund, facilitate, and initiate more rapid research and treatment development, aiming to provide a better future for people with ME and their carers and families. We are grateful for the ongoing support of our loyal supporters, who have joined with us to progress biomedical research into ME. The Hendrie Foundation continues to support our Centre of Excellence for ME proposal and related research and clinical trial activities.

We are convinced that a well-funded strategy of biomedical research into ME will lead to greater understanding, development of treatments, improved education, and more accurate information in the public domain, overcoming the ignorance, apathy, and misinformation that has persisted for decades.

Therefore, research, education, and advocacy remain the core investments that this charity makes to expedite progress in overcoming ME.

1. Research

Biomedical Research

The charity continues to make significant progress in biomedical research into ME, raising awareness and attracting more funding despite limited resources.

Centre of Excellence

Invest in ME Research has continued to promote the development of a Centre of Excellence for ME at the Norwich Research Park. We believe this is the best way forward for securing proper research and treatments for people with ME in the UK and Europe.

The charity has now funded five PhD studentships and, notably, two ME fellowships at the Quadram Institute Bioscience, building on the foundations for a UK/European Centre of Excellence for ME research in Norwich.

This year, we were proud to announce that our first fellowship has been named the Ian Gibson Fellowship for ME, in memory of our late patron and steadfast supporter, Dr Ian Gibson. In addition, the charity announced funding for a second fellowship, thanks to the wonderful support of the LunaNova company, further expanding our research capacity.

The only fully funded clinical trial for ME in the UK, supported by liMER, continues to progress, with research activities resuming as pandemic restrictions have lifted and MHRA regulations are navigated.

National and International Collaboration

We continued to bring researchers together through the European ME Research Group (EMERG), fostering collaborative proposals for European research funding and welcoming new members.

This year, we worked with our European colleagues in the European ME Alliance (EMEA) to produce the pan-European ME survey, a significant initiative to gather data and raise awareness across Europe.

Key Events and Presentations

- In December 2023, Invest in ME Research was invited to present at the NIH Washington meeting, sharing our work and perspectives on ME research with an international audience.
- We arranged and hosted the International ME Conference Week 2024, which included the Young EMERG Workshop, the 13th Biomedical Research into ME Colloquium (BRMEC13), and the 16th Invest in ME International Conference (IIMEC16), as well as EMERG/NIH meetings. We were honoured to have contributions from WHO Europe at our conference, further raising the profile of ME research at an international level.

2. Education

The charity continued its commitment to education by organising and delivering a comprehensive international conference week in 2024, including:

- The Young EMERG Workshop, supporting early-career researchers and building future research capacity.
- The BRMEC13 Colloquium and IIMEC16 Conference, bringing together researchers, clinicians, and patients from around the world.
- Collaborative meetings with EMERG and NIH, facilitating knowledge exchange and strategic planning.

We also updated and distributed the Centre of Excellence Executive Summary for MPs, ensuring policymakers are kept informed of progress and the ongoing need for investment in ME research.

3. Advocacy

National Advocacy

- DHSC Interim Plan Research Working Group: During the year, the charity contributed to the Department of Health and Social Care's

(DHSC) Interim Delivery Plan Research Working Group. Despite our active participation and detailed submissions (input04, input05), we regret to report that no substantive progress was made, and the time invested by stakeholders, including ourselves, was ultimately wasted – a huge opportunity wasted as the charity had clear proposals to expedite progress that we just ignored. We have documented our concerns and called for greater accountability and action but more years have been wasted (as we had previously predicted would happen without the urgency and direction that Invest in ME Research had advocated and proposed).

- APPG for ME Submission: liMER submitted evidence to the All-Party Parliamentary Group (APPG) for ME in November 2023, continuing to advocate for improved research funding, clinical care, and recognition for people with ME (APPG submission).

European and International Advocacy

- liMER continued to facilitate and support the European ME Alliance (EMEA), working collaboratively with national ME organisations from seventeen European countries.
- We facilitated and chaired EMEA meetings and worked with colleagues to develop and disseminate the pan-European survey.
- Our website, social media, and newsletters provided platforms for academic and patient voices, sharing up-to-date information, educational content, and opportunities for engagement.

Conclusion

Throughout the year, Invest in ME Research has continued to fund research, facilitate collaboration, and advocate for people with ME at national and international levels. Our achievements are made possible by the dedication of our volunteers and the generosity of our supporters. We remain committed to our vision of a better future for all affected by ME.

Our thanks go to our loyal supporters, many of whom are themselves severely affected by ME, for their ongoing efforts and commitment to making progress possible.

Brief statement of the charity's policy on reserves

Our reserves are held to meet expected and unexpected bills and to cover running costs and printing/stationery costs. Our objective is to use as much of our resources for the facilitation and implementation of biomedical research into ME and to raise awareness of the disease.

Details of any funds materially in deficit**Further financial review details (Optional information)**

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

The Trustees feel that it is important to try to make all of the educational material and information that we create or facilitate (whether by way of conferences, webinars or other educational material) accessible to patients and their families for free or as cheaply as possible, without compromising professionalism or standards. Many patients and carers are unable to work due to the effects of this devastating neurological disease and the lack of a proper research strategy to create treatments.

The research colloquiums are also made available to invited researchers for free or heavily subsidised in order to encourage research and international collaboration. During the year, the charity covered the costs of the Young EMERG workshop and supported EMERG members by covering their participation costs at the research colloquium and international conference.

The charity continues to feel that better education of healthcare staff via a strategy of biomedical research into ME is the key to improving conditions for people with ME and their families.

liMER aims to provide all our work for free or at cost price. We are an independent charity whose focus is on better education, better awareness, and a strategy of high-quality biomedical research into myalgic encephalomyelitis.

We hope to continue to find, fund and facilitate research and provide a means to raise more awareness of this disease – ME – and so enable a rapid resolution to be created by provision of treatments and cures from high-quality science. This benefits not only people with ME, their carers and families, but also society in general.



The Trustees also note that administrative costs are kept to an absolute minimum. No salaries are paid, and all work is carried out by volunteers, ensuring donations are used efficiently to support research, education, and advocacy. The Trustees are mindful of the need to maintain sufficient reserves to meet ongoing research commitments and to provide stability for future projects. The charity remains independent and does not accept funding that would compromise its aims or values. All income is used to further the charity's objectives and to benefit people with ME, their carers, and families.

Section F Other optional information

Section G Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Kathleen McCall	Richard Simpson
Position (eg Secretary, Chair, etc)	Chair	Trustee
Date	4 th July 2025	30 th June 2025



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name			No (if any)	CC16a
INVESTin ME RESEARCH			1153730	
Receipts and payments accounts				
For the period from	Period start date 1-Oct-23	To	Period end date 30-Sep-24	

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
General Donation , Legacies and Grants	94,944	-	-	94,944	48,597
Conferences and meetings	16,915	-	-	16,915	16,651
Brochure (CG & QQ & Journal etc)	67	-	-	67	-
Tax refund / Gift Aid	1,019	-	-	1,019	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	112,945	-	-	112,945	65,248
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	112,945	-	-	112,945	65,248

A3 Payments

Meetings and conferences	85,477	-	-	85,477	82,727
Printing of Brochures, Books & Guidelines	777	-	-	777	184
Postage, Packaging, Stationery	417	-	-	417	411
Governance, Web Services, Advertising	3,940	-	-	3,940	3,186
Fundraising Products/Equipment	216	-	-	216	696
Biomedical Research	40,710	-	-	40,710	8,349
Bank Charges	158	-	-	158	365

	-	-	-	-	-
	-	-	-	-	-
Sub total	131,695	-	-	131,695	95,918

A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-

Total payments	131,695	-	-	131,695	95,918
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Net of receipts/(payments)	- 18,751	-	-	- 18,751	- 30,670
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	438,127	-	-	438,127	-
Cash funds this year end	419,377	-	-	419,377	- 30,670

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Lloyds	419,377	-	-
		-	-	-
		-	-	-
	Total cash funds	419,377	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets	Details	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

B5 Liabilities

Details	Fund to which liability relates	Amount due (optional)	When due (optional)
		-	
		-	
		-	
		-	
		-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
<i>K. McCall</i>	Kathleen McCall	7/2/2025
<i>Richard Simpson</i>	Richard Simpson	6/30/2025



Section A

Independent Examiner's Report

Report to the trustees/ members of

Charity Name
INVEST in ME RESEARCH

On accounts for the year ended

30th September 2024

Charity no (if any)

1153730

Set out on pages

1 and 2

(remember to include the page numbers of any appendices)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 30th September 2024.

Responsibilities and basis of report

As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention (other than that disclosed below *) in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

* Please delete the words in the brackets if they do not apply.

Signed:

Paul Booth

Date:

9/7/25

Name:

PAUL BOOTH

Relevant professional qualification(s) or body (if any):

RECRUITER

Address:

30 PROVENE GDN S
SO32 9LE

Only complete if the examiner needs to highlight matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

INVEST IN ME RESEARCH

England & Wales - Charity number 1153730

Accounts



Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	01	10	2022		30	09	2023

Section A Reference and administration details

Charity name

INVEST in ME RESEARCH

Other names charity is known by

IiMER InMER IiME RESIME Invest in ME

Registered charity number (if any)

11153730

Charity's principal address

PO Box 561
 Eastleigh
 Hampshire
Postcode **SO50 0GQ**

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Kathleen McCall	Chairman		
2	Richard Simpson	Trustee		
3	Joyce Wood	Trustee		
4				
5				
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Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

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Section B Structure, governance and management

Description of the charity’s trusts

Type of governing document (eg. trust deed, constitution)	CIO Foundation Model
How the charity is constituted (eg. trust, association, company)	CHARITABLE INCORPORATED ORGANISATION
Trustee selection methods (eg. appointed by, elected by)	Appointed by Existing Trustees

Additional governance issues (Optional information)

<p>You may choose to include additional information, where relevant, about:</p> <ul style="list-style-type: none"> • policies and procedures adopted for the induction and training of trustees; • the charity’s organisational structure and any wider network with which the charity works; • relationship with any related parties; • trustees’ consideration of major risks and the system and procedures to manage them. 	<p>Invest in ME Research (IiMER) works to build relationships nationally and internationally with other organisations who promote similar aims.</p> <p>The charity has continued to chair the European ME Alliance, a collaboration of national patient organisations and charities across Europe.</p> <p>The charity also has cultivated links to many organisations, researchers, clinicians and healthcare staff and has been involved in building European groups of researchers and clinicians who will work together.</p> <p>Our objectives are to facilitate high-quality biomedical research into ME with international collaboration and development of a centre of excellence for ME that will serve UK and Europe.</p> <p>During the year and as a result of the continuing fallout from the covid pandemic then less funding of research and in person meetings was possible and the charity was able to conserve more for future work.</p>
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Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

<p>To promote and protect the well-being of sufferers of ME. To advance the education of the public in relation to ME. To promote research into causes and treatment of ME.</p>

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

The main activities are–

Organisation of annual public International ME Conferences that attract doctors, scientists, researchers, patients and carers from around the world to collaborate and share knowledge about ME.

Organisation of international research colloquiums to encourage new collaborative and cooperative possibilities for research into ME.

Creation and development of network of young researchers for ME.

Foundation and support of a collaborative European ME Research Group network for researchers to come together.

Foundation and support of a collaborative European ME Clinicians Council network for European clinicians to come together to build knowledge and expertise around ME.

Production of educational material (videos, booklets, journals and guidelines) related to ME.

Finding, facilitating and funding of biomedical research into ME.

Continuing development of the Centre of Excellence for ME model that the charity has proposed and championed since 2011.

Initiation of awareness and fund-raising activities regarding ME.

Maintenance of web sites for the charity, and European ME organisations containing educational information regarding ME and our initiatives and conferences

Creation and administering of webinars to enhance education of the public and to disseminate information around Europe regarding ME.

Advocacy work to help patients in need.

Distribution of regular newsletters to patient groups, patients, healthcare staff, media, politicians and general public regarding ME.

Chairing and supporting the European ME Alliance and participating in European collaborative projects regarding awareness of ME.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

The trustees and volunteers perform all of the charity's work for free.

The charity does not have any salaried staff.

The charity endeavours to provide services, products and information for free or as near to cost price as possible, to avoid ME patients having to bear additional burdens around costs.

The charity has a Biomedical Research Fund that allows grants for research projects to be made in an attempt to initiate more biomedical research into Myalgic Encephalomyelitis.

The charity has a peer review process for examining applications for grants.

The charity attempts to initiate more biomedical research into Myalgic Encephalomyelitis with an emphasis on international collaboration.

The charity has published our policy on grant making on our web site.

We are continuing to support our proposal to develop a UK/European Centre of Excellence for ME that will include examinations and research facility into ME and would perform biomedical research into the disease and allow proper examinations and diagnosis for ME patients.

We have initiated several major research studies for ME that take place at major UK institutes.

Section D

Achievements and performance

Summary of the main achievements of the charity during the year

Invest in ME Research (IIMER) is a small charity but has always aimed to look at the bigger picture and facilitate change based on ideas and determination.

The charity continues its dedication and commitment to improving the lives of people living with ME, and their families and carers. We do this by changing the perception and awareness of ME in scientific, media and public circles through innovation and determination to make progress in understanding the disease and overcoming flawed and erroneous beliefs about the disease.

No salaries have ever been paid in IIMER, as all work is, and has been performed by volunteers. There continues to be no wish to employ an expensive CEO or support staff as we have dedicated and committed volunteers who bring the right skills, knowledge and experience to what we need to do. This, therefore, maximises the funding that can be directed toward what we believe are the essential objectives - biomedical research into ME and events to facilitate education and collaboration in research.

The charity continues to campaign, fund, facilitate and initiate more rapid research and treatment development in order to provide a better future for people suffering from myalgic encephalomyelitis and their carers and families.

The charity continued to benefit from a loyal group of supporters who have joined with us to progress biomedical research into ME.

The charity continued to receive wonderful support from the Hendrie Foundation with regard to our development of a Centre of Excellence for ME proposal and related research and clinical trial.

The charity is convinced that a well-funded strategy of biomedical research into ME will lead to greater understanding of the disease, development of treatments, improved education and more awareness and accurate information about the disease being made into the public domain, which will then overcome the ignorance, apathy and misinformation that has been allowed to exist for decades.

Therefore, research, education and advocacy – the investment in ME research that this charity makes.

Research

Biomedical research

The charity continues to do a great deal to progress biomedical research into ME and raise awareness of the disease. Despite relatively few resources, the charity manages to accomplish a great deal and more funding was attracted during the year.

Centre of Excellence

Invest in ME Research has continued to promote the development of biomedical research to be based at a research and examination facility in the Norwich Research Park in Norfolk.

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.

The charity has now funded five PhD studentships to perform research.

The charity has also been able to fund fully the only clinical trial for ME in the UK – and one of only a handful in the world - a remarkable achievement for a small charity and its supporters. The research has necessarily been paused, and then delayed due to the effects of the pandemic. However, as more restrictions are lifted then gradually the research efforts are starting up again.

The charity was pleased to see that further investment in the research centre for ME in Norwich Research Park was made by BBSRC, thus strengthening the case for creating a focal point for research into ME in Norwich.

The charity announced the first ever Invest in ME Research Postdoctoral Fellowship for research into myalgic encephalomyelitis was to be renamed the Ian Gibson Fellowship for ME – in memory of the late Dr Ian Gibson – patron and supporter of the charity and a steadfast voice for biomedical research into ME.

The charity is finding two ME fellowships now at Quadram Institute Bioscience and builds on the foundations already made for a UK/European Centre of Excellence for ME research hub in Norwich Research Park.

To facilitate biomedical research into ME the charity also needs to fund it, in the absence of adequate funding policies from governments or research agencies.

Great faith in the charity from supporters continued through the year with much effort spent on social media applying for awards from philanthropic funding bodies with a huge effort made to encourage people to vote for the charity.

An executive summary for MPs describing the centre of excellence for ME was updated and made available to all.

The charity was instrumental in bringing researchers together in the European ME Research Group to form a collaborative proposal for European research funding in the Horizon programme. This occurred during the events organised by the charity during international ME conference week.

This also saw new members of EMERG joining the team.

2 Education

The charity decide to arrange and hold its first in person international ME conference week since the pandemic paused things in 2020.

A new research colloquium for researchers from twenty countries was created along with the public conference day.

The charity also initiated the Young EMERG – European ME Research Group Early Career Researcher Network to bring young European researchers together and build capacity for the future.

The charity arranged the first Young EMERG workshop and the team collaborated to form an international agenda.

This led to collaboration for the NIH Washington conference in December 2022 .

Invest in ME Research were invited to present at the early-career researcher even held at Washington by NIH.

The charity produced a new version of the Centre of Excellence Executive Summary for MPs document that allowed MPs to be brought up to date with the progress in development of a Centre of Excellence for ME foundation.

3 Advocacy

Europe

The charity again chaired the European ME Alliance (EMEA). Invest in ME Research is one of the founding members of EMEA, an important and unique grouping of national ME organisations from seventeen European countries that are working together to raise awareness and effect change across Europe. The charity has made enormous efforts to raise the profile of EMEA and is looking forward to new initiatives that will help all people with ME and their families.

The development of a report from the EMEA Pan European survey is being progressed with our European colleagues.

The charity arranges and chairs EMEA meetings via zoom.

The charity had finally been invited to participate in the Department of Health's Clinical Research Collaboration (UKCRC) that proposed to "drive high-quality applications for research into ME/CFS and support the research community to build capacity and capability in this field". Invest in ME Research were not invited to any of the preliminary discussions or meetings and only received an invitation to join an already created working group in September 2022.

Despite the lateness of the invitation, the charity committed effort to propose a rapid method to make progress in order to benefit patients and attended meetings to explain. The input to the meetings was documented on our web site for all to see and we were the main voice for asserting that all minutes of meetings should be made available to the public so that accountability could be seen to be made.

Throughout the year, the charity contributed new ideas to this working group to make rapid progress, attempting to overturn the intransigence of establishment inertia with regards to thinking about ME.

Internet

The charity's web site, social media sites and free newsletters continued to provide a platform for academic and patient voices concerning science and facts by providing current information, educational articles and opportunities for comment.

As well as the main website for the charity, we also maintain the web sites for some of the European organisations with which the charity is

involved.

Our thanks go to our great and loyal supporters, many of whom are severely affected by ME yet who still go to amazing lengths to make things happen.

Section E

Financial review

Brief statement of the charity's policy on reserves

Our reserves are held to meet expected and unexpected bills and to cover running costs and printing/stationery costs. Our objective is to use as much of our resources for the facilitation and implementation of biomedical research into ME and to raise awareness of the disease.

Details of any funds materially in deficit

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

The Trustees feel that it is important to try to make all of the educational material and information that we create or facilitate (whether by way of conferences, webinars or other educational material) to be accessible to patients and their families for free or as cheaply as possible without compromising professionalism or standards.

Many patients and carers are unable to work due to the effects of this devastating neurological disease and due to no proper research strategy existing to create treatments.

The research colloquiums are also made available to invited researchers for free or at a much reduced cost in order to encourage research and international collaboration.

The charity continues to feel that better education of healthcare staff via a strategy of biomedical research into ME is the key to improving conditions for people with ME and their families.

liMER aims to provide all our work for free or at cost price.

We are an independent charity whose focus is on better education, better awareness and a strategy of high-quality biomedical research into myalgic encephalomyelitis.

We hope to continue to find, fund and facilitate research and provide a means to raise more awareness of this disease – ME – and so enable a rapid resolution to be created by provision of treatments and cures from high-quality science. This benefits not only people with ME, their carers and families – but also society in general.

-

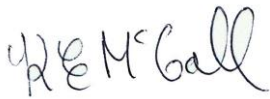

Section F

Other optional information

Section G Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Kathleen McCall	Richard Simpson
Position (eg Secretary, Chair, etc)	Chair	Trustee
Date	9 th June 2024	8 th June 2024



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name	INVESTin ME RESEARCH	No (if any)	1153730
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Receipts and payments accounts

CC16a

For the period from	Period start date 01-Oct-22	To	Period end date 30-Sep-23
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Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
General Donation , Legacies and Grants	48,597	-	-	48,597	349,485
Conferences and meetings	16,651	-	-	16,651	14,163
Tax refund / Gift Aid	-	-	-	-	163
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for	65,248	-	-	65,248	363,811
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	65,248	-	-	65,248	363,811
A3 Payments					
Printing of Brochures, Books & Postage, Packaging, Stationery	184	-	-	184	25
Governance, Web Services, Fundraising Products/Equipment	411	-	-	411	546
Meetings,	3,186	-	-	3,186	4,231
Biomedical Research	696	-	-	696	921
Bank Charges	82,727	-	-	82,727	-
	8,349	-	-	8,349	15,202
	365	-	-	365	303
	-	-	-	-	-
	-	-	-	-	-
Sub total	95,918	-	-	95,918	21,228
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	95,918	-	-	95,918	21,228
Net of receipts/(payments)	- 30,670	-	-	- 30,670	342,583
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	468,798	-	-	468,798	-
Cash funds this year end	438,127	-	-	438,127	342,583

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Lloyds	438,127	-	-
		-	-	-
		-	-	-
	Total cash funds	438,127	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
<i>K. McCall</i>	Kathleen McCall	10/07/2024
<i>Richard Simpson</i>	Richard Simpson	09/07/2024



Section A Independent Examiner's Report

Report to the trustees/ members of

INVEST in ME RESEARCH

On accounts for the year ended

30th September 2023 Charity no (if any) 1153730

Set out on pages

1 and 2

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended

Responsibilities and basis of report

As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention (other than that disclosed below *) in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

* Please delete the words in the brackets if they do not apply.

Signed: [Signature]

Date: 16/7/24

Name: PAUL BOOTH

Relevant professional qualification(s) or body (if any):

Recruitment Consultant

Address:

30 Proven Gardens
Waltham Chase, Hampshire
SO32 2LE

INVEST IN ME RESEARCH

England & Wales - Charity number 1153730

Accounts



Trustees' Annual Report for the period

		Period start date			Period end date		
From	01	10	2021	To	30	09	2022

Section A Reference and administration details

Charity name

INVEST in ME Research

Other names charity is known by

IiMER InMER IiME RESIME Invest in ME

Registered charity number (if any)

11153730

Charity's principal address

PO Box 561
 Eastleigh
 Hampshire
Postcode **SO50 0GQ**

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Kathleen McCall	Chairman		
2	Richard Simpson	Trustee		
3	Joyce Wood	Trustee		
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

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Section B Structure, governance and management

Description of the charity’s trusts

Type of governing document (eg. trust deed, constitution)	CIO Foundation Model
How the charity is constituted (eg. trust, association, company)	CHARITABLE INCORPORATED ORGANISATION
Trustee selection methods (eg. appointed by, elected by)	Appointed by Existing Trustees

Additional governance issues (Optional information)

<p>You may choose to include additional information, where relevant, about:</p> <ul style="list-style-type: none"> • policies and procedures adopted for the induction and training of trustees; • the charity’s organisational structure and any wider network with which the charity works; • relationship with any related parties; • trustees’ consideration of major risks and the system and procedures to manage them. 	<p>Invest in ME Research (IiMER) works to build relationships nationally and internationally with other organisations who promote similar aims.</p> <p>The charity has continued to chair the European ME Alliance, a collaboration of national patient organisations and charities across Europe.</p> <p>The charity also has cultivated links to many organisations, researchers, clinicians and healthcare staff and has been involved in building European groups of researchers and clinicians who will work together.</p> <p>Our objectives are to facilitate high-quality biomedical research into ME with international collaboration and development of a centre of excellence for ME that will serve UK and Europe.</p> <p>During the year and as a result of the continuing fallout from the covid pandemic then less funding of research and in person meetings was possible and the charity was able to conserve more for future work.</p>
--	---

Section C Objectives and activities

<p>Summary of the objects of the charity set out in its governing document</p>	<p>To promote and protect the well-being of sufferers of ME. To advance the education of the public in relation to ME. To promote research into causes and treatment of ME.</p>
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Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

The main activities are–

Organisation of annual public International ME Conferences that attract doctors, scientists, researchers, patients and carers from around the world to collaborate and share knowledge about ME.

Organisation of international research colloquiums to encourage new collaborative and cooperative possibilities for research into ME.

Creation and development of network of young researchers for ME.

Foundation and support of a collaborative European ME Research Group network for researchers to come together.

Foundation and support of a collaborative European ME Clinicians Council network for European clinicians to come together to build knowledge and expertise around ME.

Production of educational material (videos, booklets, journals and guidelines) related to ME.

Finding, facilitating and funding of biomedical research into ME.

Continuing development of the Centre of Excellence for ME model that the charity has proposed and championed since 2011.

Initiation of awareness and fund-raising activities regarding ME.

Maintenance of web sites for the charity, and European ME organisations containing educational information regarding ME and our initiatives and conferences

Creation and administering of webinars to enhance education of the public and to disseminate information around Europe regarding ME.

Advocacy work to help patients in need.

Distribution of regular newsletters to patient groups, patients, healthcare staff, media, politicians and general public regarding ME.

Chairing the European ME Alliance and participating in European collaborative projects regarding awareness of ME.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

The trustees and volunteers perform all of the charity's work for free.

The charity does not have any salaried staff.

The charity endeavours to provide services, products and information for free or as near to cost price as possible, to avoid ME patients having to bear additional burdens around costs.

The charity has a Biomedical Research Fund that allows grants for research projects to be made in an attempt to initiate more biomedical research into Myalgic Encephalomyelitis.

The charity has a peer review process for examining applications for grants.

The charity attempts to initiate more biomedical research into Myalgic Encephalomyelitis with an emphasis on international collaboration.

The charity has published our policy on grant making on our web site.

We are continuing to support our proposal to develop a UK/European Centre of Excellence for ME that will include examinations and research facility into ME and would perform biomedical research into the disease and allow proper examinations and diagnosis for ME patients.

We have initiated several major research studies for ME that take place at major UK institutes.

Section D

Achievements and performance

Summary of the main achievements of the charity during the year

Invest in ME Research (IIMER) is a comparatively small charity. Yet the charity continues its dedication and commitment to improving the lives of people living with ME, and their families and carers. We do this by changing the perception and awareness of ME in scientific, media and public circles through innovation and determination to make progress in understanding the disease and overcoming flawed and erroneous beliefs about the disease.

No salaries have ever been paid in IIMER, as all work is, and has been performed by volunteers. There continues to be no wish to employ an expensive CEO or support staff as we have dedicated and committed volunteers who bring the right skills, knowledge and experience to what we need to do. This, therefore, maximises the funding that can be directed toward what we believe are the essential objectives - biomedical research into ME and events to facilitate education and collaboration in research.

The charity continues to campaign, fund, facilitate and initiate more rapid research and treatment development in order to provide a better future for people suffering from myalgic encephalomyelitis and their carers and families.

The charity continued to benefit from a loyal group of supporters who have joined with us to progress biomedical research into ME.

The charity continued to receive wonderful support from the Hendrie Foundation with regard to our development of a Centre of Excellence for ME proposal and related research and clinical trial.

The charity is convinced that a well-funded strategy of biomedical research into ME will lead to greater understanding of the disease, development of treatments, improved education and more awareness and accurate information about the disease being made into the public domain, which will then overcome the ignorance, apathy and misinformation that has been allowed to exist for decades.

Therefore, research, education and advocacy – the investment in ME research that this charity makes.

Research

Biomedical research

The charity continues to do a great deal to progress biomedical research into ME and raise awareness of the disease. Despite relatively few resources, the charity manages to accomplish a great deal and more funding was attracted during the year.

Centre of Excellence

Invest in ME Research has continued to promote the development of biomedical research to be based at a research and examination facility in the Norwich Research Park in Norfolk.

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.

The charity has now funded five PhD studentships to perform research. The charity has also been able to fund fully the only clinical trial for ME in the UK – and one of only a handful in the world - a remarkable achievement for a small charity and its supporters. The research has

necessarily been paused, and then delayed due to the effects of the pandemic. However, as more restrictions are lifted then gradually the research efforts are starting up again.

The charity was pleased to see that further investment in the research centre for ME in Norwich Research Park was made by BBSRC, thus strengthening the case for creating a focal point for research into ME in Norwich.

The charity announced the funding for its first ever first Invest in ME Research Postdoctoral Fellowship for research into myalgic encephalomyelitis. In partnership with Quadram Institute Bioscience this new position has been created to continue and extend research into ME and builds on the foundations already made for a UK/European Centre of Excellence for ME research hub in Norwich Research Park.

To facilitate biomedical research into ME the charity also needs to fund it, in the absence of adequate funding policies from governments or research agencies.

Great faith in the charity from supporters continued through the year with much effort spent on social media applying for awards from philanthropic funding bodies with a huge effort made to encourage people to vote for the charity.

Donations and Legacies

During the year the charity was a recipient of a large donation from a donor who currently wished to remain anonymous. This donation was for use in the charity's funding of a strategy of biomedical research at the centre of excellence development in Norwich Research Park. The charity was also a recipient of a legacy from a supporter who sadly passed away. All at the charity are humbled by these acts and we know that they will be put to good use.

We also received donations from groups and individuals as well from fund-raising campaigns from our supporters and the efforts of so many people to help us make progress have been truly outstanding..

2 Education

Due to ongoing concerns with the consequences of the pandemic the charity elected to organise its eleventh biomedical research into ME colloquium as a virtual event. Nevertheless, this two-day virtual meeting still attracted almost ninety accepted invitations from over a dozen countries around the world. The theme for the Colloquium was - ME and Long Covid: Emerging insights in mechanisms and complexity of post-viral fatigue.

The European ME Research Group (EMERG) published a paper using the output from the #BRMEC10 research colloquium organised by the charity to progress understanding of ME amongst researchers.

As chair of the European ME Alliance the charity organised and set up a virtual roundtable meeting and collaborated with the European Federation of Neurological Alliances to discuss issues, educate and find solutions. The webinar title was ME/CFS in Europe and it was the second

such webinar that the charity organised to benefit the public and people with ME by discussing issues and attempting to find solutions by identifying a focus group of stakeholders, and publicising ME education and research.

The charity also arranged and facilitated another webinar involving the Nordic areas – entitled ME/CFS in the Nordic Countries and videos of the discussions were provided for free for all to see.

In order to facilitate education and progress in the Eastern side of Europe the charity organised a webinar for the Balkan countries of Croatia, Slovenia and Serbia - ME and post covid in the Balkans and made videos of the webinar. Invited guests included the Serbian Health minister and a range of European researchers.

The charity produced a new version of the Centre of Excellence Executive Summary for MPs document that allowed MPs to be brought up to date with the progress in development of a Centre of Excellence for ME foundation.

3 Advocacy

Europe

The charity again chaired the European ME Alliance (EMEA). Invest in ME Research is one of the founding members of EMEA, an important and unique grouping of national ME organisations from seventeen European countries that are working together to raise awareness and effect change across Europe. The charity has made enormous efforts to raise the profile of EMEA and is looking forward to new initiatives that will help all people with ME and their families.

The development of a report from the EMEA Pan European survey is being progressed with our European colleagues.

The charity arranges and chairs EMEA meetings via zoom.

The charity has advocated for many years that the NICE guidelines for ME were unfit for purpose, a view that the Guidelines Director for NICE eventually agreed upon. Once the review of the guidelines was completed by NICE then the charity commented and made the point that the new guidelines could have been written fourteen years before, due to the lack of new knowledge and the previously stated view of flawed recommendations for treatments in the old guidelines, a point that nobody else seemed to make.

The charity continued to explain how the guidelines were not without concern as there was no mandatory instruction to follow them by all healthcare providers, something that has been eventually discovered by many who see a slow uptake in these guidelines. The charity published articles on this to aid the public in understanding the issues.

The charity was finally invited to participate in the Department of Health's Clinical Research Collaboration (UKCRC) that proposed to "drive high-quality applications for research into ME/CFS and support the research community to build capacity and capability in this field".

Invest in ME Research were not invited to any of the preliminary discussions or meetings and only received an invitation to join an already created working group in September 2022.

Despite the lateness of the invitation the charity committed effort to propose a rapid method to make progress in order to benefit patients and attended meetings to explain. The input to the meetings was documented on our web site for all to see and we were the main voice for asserting that all minutes of meetings should be made available to the public so that accountability could be seen to be made.

Internet

The charity's web site, social media sites and free newsletters continued to provide a platform for academic and patient voices concerning science and facts by providing current information, educational articles and opportunities for comment.

As well as the main website for the charity, we also maintain the web sites for some of the European organisations with which the charity is involved.

In this, we have been supported by the continued fundraising initiative – Let's Do It For ME (LDIFME) – a patient-driven campaign to raise awareness and vital funds for the proposed Invest in ME Research UK centre of excellence for ME. LDIFME includes many supporters who have given their efforts to make change possible.

Our thanks go to our great and loyal supporters, many of whom are severely affected by ME yet who still go to amazing lengths to make things happen.

Section E

Financial review

Brief statement of the charity's policy on reserves

Our reserves are held to meet expected and unexpected bills and to cover running costs and printing/stationery costs. Our objective is to use as much of our resources for the facilitation and implementation of biomedical research into ME and to raise awareness of the disease.

Details of any funds materially in deficit

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

The Trustees feel that it is important to try to make all of the educational material and information that we create or facilitate (whether by way of conferences, webinars or other educational material) to be accessible to patients and their families for free or as cheaply as possible without compromising professionalism or standards.

Many patients and carers are unable to work due to the effects of this devastating neurological disease and due to no proper research strategy existing to create treatments.

The research colloquiums are also made available to invited researchers for free or at a much reduced cost in order to encourage research and international collaboration.

The charity continues to feel that better education of healthcare staff via a strategy of biomedical research into ME is the key to improving conditions for people with ME and their families.

liMER aims to provide all our work for free or at cost price.

We are an independent charity whose focus is on better education, better awareness and a strategy of high-quality biomedical research into myalgic encephalomyelitis.

We hope to continue to find, fund and facilitate research and provide a means to raise more awareness of this disease – ME – and so enable a rapid resolution to be created by provision of treatments and cures from high-quality science. This benefits not only people with ME, their carers and families – but also society in general.

Section F



Other optional information

Section G

Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Kathleen McCall	Richard Simpson
Position (eg Secretary, Chair, etc)	Chair	Trustee
Date	19 th June 2023	18 th June 2023



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name	No (if any)
INVESTin ME RESEARCH	1153730

Receipts and payments accounts

CC16a

For the period from	Period start date	To	Period end date
	01-Oct-21		30-Sep-22

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
General Donation , Legacies and Grants	349,485	-	-	349,485	161,716
Conferences and meetings	14,163	-	-	14,163	-
Brochure (CG & QQ & Journal etc)	-	-	-	-	-
Tax refund / Gift Aid	163	-	-	163	224
Fund-raising Charity Activities	-	-	-	-	50
Bank a/c Interest	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	363,811	-	-	363,811	161,990
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	363,811	-	-	363,811	161,990
A3 Payments					
Printing of Brochures, Books & Guidelines	25	-	-	25	149
Postage, Packaging, Stationery	546	-	-	546	437
Governance, Web Services, Advertising	4,231	-	-	4,231	2,986
Fundraising Products/Equipment	921	-	-	921	-
Biomedical Research	15,202	-	-	15,202	204,601
Bank Charges	303	-	-	303	356
	-	-	-	-	-
	-	-	-	-	-
Sub total	21,228	-	-	21,228	208,529
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	21,228	-	-	21,228	208,529
Net of receipts/(payments)	342,583	-	-	342,583	- 46,539
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	126,215	-	-	126,215	-
Cash funds this year end	468,798	-	-	468,798	- 46,539

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Lloyds	468,798	-	-
		-	-	-
		-	-	-
	Total cash funds	468,798	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
<i>K. McCall</i>	Kathleen McCall	21/06/2023
<i>Richard Simpson</i>	Richard Simpson	21/06/2023



Section A

Independent Examiner's Report

**Report to the trustees/
members of**

Trust Name
INVEST in ME RESEARCH

**On accounts for the year
ended**

30th September 2022

**Charity no
(if any)**

1153730

Set out on pages

1 and 2

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended

**Responsibilities and
basis of report**

As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

**Independent
examiner's statement**

I have completed my examination. I confirm that no material matters have come to my attention (other than that disclosed below *) in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

** Please delete the words in the brackets if they do not apply.*

Signed:

Date:

26/8/2023

Name:

PAUL BOOTH

**Relevant professional
qualification(s) or body
(if any):**

N/A

Address:

30 PROVENG GARDENS
SOUTHAMPTON
SO3A 2LE

INVEST IN ME RESEARCH

England & Wales - Charity number 1153730

Accounts



Trustees' Annual Report for the period

		Period start date			Period end date		
From	01	10	2020	To	30	09	2021

Section A Reference and administration details

Charity name

INVEST in ME Research

Other names charity is known by

IiMER InMER IiME RESIME Invest in ME

Registered charity number (if any)

11153730

Charity's principal address

PO Box 561
 Eastleigh
 Hampshire
Postcode **SO50 0GQ**

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Kathleen McCall	Chairman		
2	Richard Simpson	Trustee		
3	Joyce Wood	Trustee		
4				
5				
6				
7				
8				
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17				
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19				
20				

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

--

Section B Structure, governance and management

Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	CIO Foundation Model
How the charity is constituted (eg. trust, association, company)	CHARITABLE INCORPORATED ORGANISATION
Trustee selection methods (eg. appointed by, elected by)	Appointed by Existing Trustees

Additional governance issues (Optional information)

<p>You may choose to include additional information, where relevant, about:</p> <ul style="list-style-type: none"> • policies and procedures adopted for the induction and training of trustees; • the charity's organisational structure and any wider network with which the charity works; • relationship with any related parties; • trustees' consideration of major risks and the system and procedures to manage them. 	<p>Invest in ME Research (IiMER) works to build relationships nationally and internationally with other organisations who promote similar aims.</p> <p>IiMER has continued to chair the European ME Alliance, a collaboration of national patient organisations and charities across Europe.</p> <p>The charity also has cultivated links to many organisations, researchers, clinicians and healthcare staff and has initiated and supported European groups of researchers and clinicians who work together in research and clinical areas.</p> <p>Our objectives are to facilitate high-quality biomedical research into ME with international collaboration.</p>
--	--

Section C Objectives and activities

<p>Summary of the objects of the charity set out in its governing document</p>	<p>To promote and protect the well-being of sufferers of ME. To advance the education of the public in relation to ME. To promote research into causes and treatment of ME.</p>
---	---

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

The main activities are–

Finding, facilitating and funding of biomedical research into ME.

Continuing development of the Centre of Excellence for ME model that the charity has proposed and championed since 2011.

Initiation of awareness and fund-raising activities regarding ME.

Organisation of annual public International ME Conferences that attract doctors, scientists, researchers, patients and carers from around the world.

Organisation of international research colloquiums to encourage new collaborative and cooperative possibilities for research into ME.

Creation and development of network of young researchers for ME.

Foundation and support of a collaborative European ME Research Group network for researchers to come together.

Foundation and support of a collaborative European ME Clinicians Council network for European clinicians to come together to build knowledge and expertise around ME.

Production of educational material (videos, booklets, journals and guidelines) related to ME.

Maintenance of web sites for the charity, and European ME organisations containing educational information regarding ME and our initiatives and conferences

Creation and administering of webinars to enhance education of the public regarding ME.

Advocacy work to help patients in need.

Distribution of regular newsletters to patient groups, patients, healthcare staff, media, politicians and general public regarding ME.

Chairing the European ME Alliance and participating in European collaborative projects regarding awareness of ME.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

The trustees and volunteers perform all of the charity's work for free.

The charity does not have any salaried staff.

The charity endeavours to provide services, products and information for free or as near to cost price as possible, to avoid ME patients having to bear additional burdens around costs.

The charity has a Biomedical Research Fund that allows grants for research projects to be made in order to continue developing the strategy of biomedical research into Myalgic Encephalomyelitis.

The charity has a peer review process for examining applications for grants.

The charity attempts to initiate more biomedical research into Myalgic Encephalomyelitis with an emphasis on international collaboration.

The charity has published our policy on grant making on our web site.

We are continuing to support our proposal to develop a UK/European Centre of Excellence for ME that will include examinations and research facility into ME and would perform biomedical research into the disease and allow proper examinations and diagnosis for ME patients.

We have initiated several major research studies for ME that take place at major UK institutes.

Section D

Achievements and performance

Section D

Achievements and performance

Summary of the main achievements of the charity during the year

Invest in ME Research is a comparatively small charity.

Yet the charity continues to change the perception and awareness of ME in scientific, media and public circles through innovation and dedication.

No salaries have ever been paid in IiMER, as all work is voluntary. We continue to see no need to employ an expensive CEO as we have dedicated and committed volunteers who bring the right skills, knowledge, experience and, most importantly, passion to what we need to do. In this way we maximise the funding that we are able to direct toward biomedical research into ME and events to facilitate education and collaboration in research.

The charity continued to benefit from a loyal group of supporters who have joined with us to progress biomedical research into ME.

The charity continues to campaign for and facilitate more rapid research and treatment development in order to provide a better future for people suffering from myalgic encephalomyelitis and their carers and families.

The charity continued to receive wonderful support from the Hendrie Foundation with regard to our development of a Centre of Excellence for ME proposal and related research.

The charity again chaired the European ME Alliance (EMEA). Invest in ME Research is one of the founding members of EMEA, an important grouping of national ME organisations from seventeen European countries that are working together to raise awareness and effect change across Europe. The charity has made enormous efforts to raise the profile of EMEA and is looking forward to new initiatives that will help all people with ME and their families.

As chair of EMEA IiMER organised the first EMEA Roundtable webinar – ME/CFS in Europe, which had Tedros Adhanom Ghebreyesus from the World Health Organisation opening the event.

The idea was to form a Roundtable of European Stakeholders and Policymakers.

The charity also organised the videos from the event and these are available on the EMEA website with all presentations from the event.

The charity joined our EMEA colleagues in organising a pan

European survey of patients - the first of its kind comparing the situation and experiences of ME-patients across European countries.

The charity continues to do a great deal to progress biomedical research into ME and raise awareness of the disease. Despite relatively few resources the charity manages to accomplish a great deal.

The charity has now funded five PhD studentships to perform research. One of these will be in association with collaborative work being carried out between the UK and Sweden via collaboration with University of Uppsala and also in Norway with the collaboration in Trondheim.

The charity has also been able to fund fully the only clinical trial for ME in the UK – and one of only a few in the world for ME - a remarkable achievement for a small charity and its supporters.

The charity's web site, social media sites and free newsletters continued to provide a platform for academic and patient voices concerning science and facts by providing current information, educational articles and opportunities for comment.

As well as the main website for the charity we also maintain the web sites for some of the European organisations with which the charity is involved.

Invest in ME Research has continued to promote the development of biomedical research to be based at a research and examination facility in the Norwich Research Park in Norfolk – a UK/European Centre of Excellence for ME.

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.

In this we have been supported by the visionary fundraising initiative – Let's Do It For ME (LDIFME) – a patient-driven campaign to raise awareness and vital funds for the proposed Invest in ME Research UK centre of excellence for ME. LDIFME includes many supporters who have given their efforts to make change possible.

The charity had announced the annual International ME

Conference Week in London for May/June 2021. However, despite the many months of planning and organising exciting and stimulating agendas and initiatives for these events, the charity had to cancel all of this due to the Covid-19 pandemic and its effects on life in all countries.

Due to the restrictions and safety requirements all of the in-person conference week events in 2021 were cancelled.

The charity did, however, host the BRMEC10 international biomedical research into ME Colloquium – as an online zoom meeting. In order to make a difference research which were now not able to be achieved due to face to face meetings the charity worked with the European ME Research Group (EMERG) to prepare a different type of agenda that brought forward hypotheses for different areas of ME research.

This proved a great success and was well received by the international audience and a paper will be issued for publication in a major journal.

The pandemic has severely affected the charity's plans and many other related initiatives and projects have been affected.

Fundraising was also affected by this situation as many fundraising events were not able to take place - although despite this some social media events were able to take place to raise funds and Invest in ME Research Supporters won a Movement for Good Award from Ecclesiastical

The research being funded by the charity was also drastically affected with many research institutes being closed or reduced in function.

The charity repeatedly requested that NICE remove the recommendation for Graded Exercise Treatment (GET) as well as Cognitive Behaviour Therapy (CBT) from its guidelines for ME as these are shown to be deleterious to the health of people with ME. The charity argued that new guidelines being delayed leaves the door open for patients to be mistreated. In December 2020 NICE partially acceded to the charity's request by adding a comment to this effect.

When NICE published their new guidelines the charity responded with extensive and constructive commentary and appraisal – both to the draft and to the final guidelines.

The charity conversed directly with the NICE CEO to ensure that patients' rights and welfare continued to be foremost when publishing new guidelines for ME.

Ian Gibson

In April 2021 our advisor, and friend of the charity, Dr Ian Gibson sadly passed away and we commented on our web sites and social media on the effect that Dr Gibson has on representing patients' rights and raising awareness of the disease and of the work of the charity.

Various fundraising activities took place with the support of a wonderful set of supporters.

The charity had entrants for the London Royal Parks Half Marathon.

Multiple online events and campaigns were held to raise funds for research and more awareness of ME and our supporters combined to promote the charity in several online competitions which were several times successful in winning awards.

All of the funds received go fully to funding or facilitating research into ME.

Section E

Financial review

Brief statement of the charity's policy on reserves

Our reserves are held to meet expected and unexpected bills and to cover running costs and printing/stationery costs. Our objective is to use as much of our resources for the facilitation and implementation of biomedical research into ME and to raise awareness of the disease.

Details of any funds materially in deficit

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

The charity trustees feel that the best way to make rapid changes in helping people with ME is to fund and facilitate high quality biomedical research into the disease, and that this is best accomplished by developing the Centre of Excellence for ME in Norwich Research Park using the knowledge, experience, facilities and capabilities of the unique talent that exists there. This could be a UK/European hub for research.

To this end the charity has devoted most of its research funding toward this goal and to support the establishment of a European ME research network that can collaborate and share knowledge.

Our research colloquiums and conferences also add to this by bringing together researchers and clinicians from around the world and allowing exchange with patient organisations and patients and carers.

it is important to try to make the conferences and the educational material accessible to patients and their families, many of whom are unable to work due to the effects of this devastating neurological disease and due to no proper research strategy existing to create treatments.

The research colloquiums are also made available to invited researchers for free or at a much reduced cost in order to encourage research and international collaboration.

The charity continues to feel that better education of healthcare staff is the key to improving conditions for people with ME and their families. liMER aims to provide all our work for free or at cost price.

We are an independent charity whose focus is on better education, better awareness and a strategy of high-quality biomedical research into myalgic encephalomyelitis.

We hope to continue to find, fund and facilitate research and provide a means for patient groups to raise more awareness of this disease – ME – and so enable a rapid resolution to be created by provision of treatments and cures from high-quality science.

Section F



Other optional information

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Section G Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Kathleen McCall	Richard Simpson
Position (eg Secretary, Chair, etc)	Chair	Trustee
Date	16 th June 2022	15 th June 2022



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name	No (if any)
INVEST in ME RESEARCH	1153730

CC16a

Receipts and payments accounts

For the period from	Period start date	To	Period end date
	01-Oct-20		30-Sep-21

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
General Donation , Legacies and Grants	161,716	-	-	161,716	52,672
Conferences and meetings	-	-	-	-	7,443
Printed material (guidelines, booklets, brochures, cards, journals etc)	-	-	-	-	242
Tax refund / Gift Aid	224	-	-	224	650
Fund-raising Charity Activities	50	-	-	50	-
Bank a/c Interest	-	-	-	-	19
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	161,990	-	-	161,990	61,026
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	161,990	-	-	161,990	61,026
A3 Payments					
Meetings and conferences	-	-	-	-	13,448
Printing of Brochures, Books & Guidelines	149	-	-	149	-
Postage, Packaging, Stationery	437	-	-	437	95
Governance, Web Services, Advertising	2,986	-	-	2,986	193
Fundraising Products/Equipment	-	-	-	-	46
Biomedical Research	204,601	-	-	204,601	217,797
Bank Charges	356	-	-	356	376
	-	-	-	-	-
	-	-	-	-	-
Sub total	208,529	-	-	208,529	231,956
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	208,529	-	-	208,529	231,956
Net of receipts/(payments)	- 46,539	-	-	- 46,539	- 170,930
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	172,754	-	-	172,754	-
Cash funds this year end	126,215	-	-	126,215	- 170,930

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Lloyds	126,215	-	-
		-	-	-
		-	-	-
	Total cash funds	126,215	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
<i>K. McCall</i>	Kathleen McCall	15/06/2022
<i>Richard Simpson</i>	Richard Simpson	13/06/2022



Section A

Independent Examiner's Report

**Report to the trustees/
members of**

INVEST in ME RESEARCH

**On accounts for the year
ended**

30th September 2021

**Charity no
(if any)**

1153730

Set out on pages

1 and 2

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 30/09/2020.

**Responsibilities and
basis of report**

As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

**Independent
examiner's statement**

I have completed my examination. I confirm that no material matters have come to my attention (other than that disclosed below *) in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

** Please delete the words in the brackets if they do not apply.*

Signed:

Date:

2/7/2022

Name:

Paul Booth

**Relevant professional
qualification(s) or body
(if any):**

Address:

30 Provene Gardens

Waltham Chase

S032 2LE

Only complete if the examiner needs to highlight matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

INVEST IN ME RESEARCH

England & Wales - Charity number 1153730

Accounts



Trustees' Annual Report for the period

		Period start date			Period end date		
From	01	10	2019	To	30	09	2020

Section A Reference and administration details

Charity name

INVEST in ME Research

Other names charity is known by

IiMER InMER IiME RESIME

Registered charity number (if any)

11153730

Charity's principal address

PO Box 561
 Eastleigh
 Hampshire
Postcode **SO50 0GQ**

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Kathleen McCall	Chairman		
2	Richard Simpson	Trustee		
3	Joyce Wood	Trustee		
4	Elizabeth McCall	Trustee		
5				
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19				
20				

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

--

Section B Structure, governance and management

Description of the charity’s trusts

Type of governing document (eg. trust deed, constitution)	CIO Foundation Model
How the charity is constituted (eg. trust, association, company)	CHARITABLE INCORPORATED ORGANISATION
Trustee selection methods (eg. appointed by, elected by)	Appointed by Existing Trustees

Additional governance issues (Optional information)

<p>You may choose to include additional information, where relevant, about:</p> <ul style="list-style-type: none"> • policies and procedures adopted for the induction and training of trustees; • the charity’s organisational structure and any wider network with which the charity works; • relationship with any related parties; • trustees’ consideration of major risks and the system and procedures to manage them. 	<p>Invest in ME Research (IIMER) works to build relationships nationally and internationally with other organisations who promote similar aims.</p> <p>In particular, IIMER has continued to chair the European ME Alliance, a collaboration of national patient organisations and charities across Europe.</p> <p>The charity also has cultivated links to many organisations, researchers, clinicians and healthcare staff and has been involved in building European groups of researchers and clinicians who will work together.</p> <p>Our objectives are to facilitate high-quality biomedical research into ME with international collaboration.</p>
--	---

Section C Objectives and activities

<p>Summary of the objects of the charity set out in its governing document</p>	<p>To promote and protect the well-being of sufferers of ME. To advance the education of the public in relation to ME. To promote research into causes and treatment of ME.</p>
---	---

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

The main activities are–

Organisation of annual public International ME Conferences that attract doctors, scientists, researchers, patients and carers from around the world.

Organisation of international research colloquiums to encourage new collaborative and cooperative possibilities for research into ME.

Creation and development of network of young researchers for ME.

Foundation and support of a collaborative European ME Research Group network for researchers to come together.

Foundation and support of a collaborative European ME Clinicians Council network for European clinicians to come together to build knowledge and expertise around ME.

Production of educational material (videos, booklets, journals and guidelines) related to ME.

Finding, facilitating and funding of biomedical research into ME.

Initiation of awareness and fund-raising activities regarding ME.

Maintenance of web sites for the charity, and European ME organisations containing educational information regarding ME and our initiatives and conferences

Creation and administering of webinars to enhance education of the public regarding ME.

Advocacy work to help patients in need.

Distribution of regular newsletters to patient groups, patients, healthcare staff, media, politicians and general public regarding ME.

Chairing the European ME Alliance and participating in European collaborative projects regarding awareness of ME.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

The trustees and volunteers perform all of the charity's work for free.

The charity does not have any salaried staff.

The charity endeavours to provide services, products and information for free or as near to cost price as possible, to avoid ME patients having to bear additional burdens around costs.

The charity has a Biomedical Research Fund that allows grants for research projects to be made in an attempt to initiate more biomedical research into Myalgic Encephalomyelitis.

The charity has a peer review process for examining applications for grants.

The charity attempts to initiate more biomedical research into Myalgic Encephalomyelitis with an emphasis on international collaboration.

The charity has published our policy on grant making on our web site.

We are continuing to support our proposal to develop a UK/European Centre of Excellence for ME that will include examinations and research facility into ME and would perform biomedical research into the disease and allow proper examinations and diagnosis for ME patients.

We have initiated several major research studies for ME that take place at major UK institutes.

Section D

Achievements and performance

Summary of the main achievements of the charity during the year

Invest in ME Research is a comparatively small charity.

Yet the charity continues to change the perception and awareness of ME in scientific, media and public circles through innovation and dedication.

No salaries have ever been paid in IiMER, as all work is voluntary. We see no need to employ an expensive CEO as we have dedicated and committed volunteers who bring the right skills, knowledge and experience to what we need to do and we maximise the funding that we are able to direct toward biomedical research into ME and events to facilitate education and collaboration in research.

The charity continued to benefit from a loyal group of supporters who have joined with us to progress biomedical research into ME.

The charity continues to campaign, facilitate, and initiate more rapid research and treatment development in order to provide a better future for people suffering from myalgic encephalomyelitis and their carers and families.

The charity continued to receive wonderful support from the Hendrie Foundation with regard to our development of a Centre of Excellence for ME proposal and related research and the charity.

The charity again chaired the European ME Alliance (EMEA). Invest in ME Research is one of the founding members of EMEA, an important grouping of national ME organisations from seventeen European countries that are working together to raise awareness and effect change across Europe. The charity has made enormous efforts to raise the profile of EMEA and is looking forward to new initiatives that will help all people with ME and their families.

The charity continues to do a great deal to progress biomedical research into ME and raise awareness of the disease. Despite relatively few resources the charity manages to accomplish a great deal.

The charity has now funded five PhD studentships to perform research. One of these will be in association with collaborative work being carried out between the UK and Sweden via collaboration with University of Uppsala. The charity has also been able to fund fully the only clinical trial for ME in the UK – and one of only two in Europe - a remarkable achievement for a small charity and its supporters.

The charity's web site, social media sites and free newsletters continued to provide a platform for academic and patient voices concerning science and facts by providing current information, educational articles and opportunities for comment.

As well as the main website for the charity we also maintain the web sites for some of the European organisations with which the charity is involved.

Invest in ME Research has continued to promote the development of biomedical research to be based at a research and examination facility in the Norwich Research Park in Norfolk.

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.

In this we have been supported by the visionary fundraising initiative – Let's Do It For ME (LDIFME) – a patient-driven campaign to raise awareness and vital funds for the proposed Invest in ME Research UK centre of excellence for ME. LDIFME includes many supporters who have given their efforts to make change possible.

In September 2019 the charity arranged an Update on Initiatives for ME public meeting during Norwich Science Festival Week thanks to funding from an Awards for All grant.

Two distinct parts to the evening - the first on the initiatives created and underway in relation to research and the clinical side of ME, revolving around the centre of research in Norwich Research Park.

The second part of the evening was oriented toward experiences for ME patients - with a presentation on pacing for patients from the European ME Alliance.

In November 2019 the charity organised and held new meetings in London for both the European ME Research Group (EMERG) and the European ME Clinicians Council (EMECC). These groups have representatives from ten European countries with the aim to increase collaboration in research and clinical expertise around ME in Europe and plan a strategy of biomedical research into ME.

The charity also produced a small booklet giving an overview of how ME affects a community. The booklet WE – A Community and ME – presented ME as seen from

other parts of the community, looking at the perceptions and reasons for those perceptions from others who deal with people with ME.

Thanks to funding from an Awards for All grant the charity has been able to have a number of copies printed and these have been distributed to assist in raising awareness of ME.

In December 2019 Invest in ME Research announced its pledge of £500,000 for continued research into ME in Norwich Research Park, UK (NRP).

This major investment would build on the foundations already made for a UK/European Centre of Excellence for ME research hub in Norwich Research Park.

The pledge covered joint funding of a PhD position in partnership with University of East Anglia and over 70% of the required funding for a clinical trial of Faecal Microbiota Transplantation (FMT) being performed alongside other high-quality biomedical research at the Quadram Institute (QI).

In January 2020 Invest in ME Research and the Quadram Institute arranged a Public Engagement Event in Norwich that allowed the public to be made aware of the researchers and the research being funded by the charity, with particular emphasis on the planned clinical trial to be performed at Quadram Institute.

In February 2020 An International Clinicians Workshop was announced by the charity as part of the annual International ME Conference week that the charity has organised for fifteen years. This new event was intended to improve clinical knowledge and collaboration amongst clinicians. The international ME conference week would include fifteenth annual public international ME conference in London which regularly attracts researchers, clinicians and patients from twenty countries. It would also include tenth international biomedical research into ME Colloquium that encourages collaboration and sharing of knowledge amongst researchers and has now become the largest biomedical research for ME colloquium in the world.

The charity was also planning to continue its initiative of encouraging young researchers into the field of ME research by holding the third Thinking the Future for ME conference for young researchers.

These events formed the annual international ME conference week which has become a regular fixture in the ME calendar.

However, despite the many months of planning and organising exciting and stimulating agendas and initiatives

for these events, the charity had to cancel all of this due to the Covid-19 pandemic and its effects on life in all countries.

The pandemic has severely affected the charity's plans and many other related initiatives and projects have been affected.

Fundraising was also affected by this situation as many fundraising events were not able to take place - although despite this some social media events were able to take place to raise funds and Invest in ME Research Supporters won a Movement for Good Award from Ecclesiastical

The research being funded by the charity was also drastically affected with many research institutes being closed or reduced in function.

The charity reported on the National Institute for Health and Care Excellence (NICE) draft guidelines for ME with an extensive appraisal of the document.

In July 2020 the charity was able to announce an increase in funding for the clinical trial – thus being able to fund fully the whole trial. This was thanks to an additional commitment by the Hendrie Foundation to underwrite any shortfall in the funding that the charity raised whilst the charity attempted to raise the remaining amount.

Section E

Financial review

Brief statement of the charity's policy on reserves

Our reserves are held to meet expected and unexpected bills and to cover running costs and printing/stationery costs. Our objective is to use as much of our resources for the facilitation and implementation of biomedical research into ME and to raise awareness of the disease.

Details of any funds materially in deficit

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

The Trustees feel that it is important to try to make the conferences and the educational material accessible to patients and their families, many of whom are unable to work due to the effects of this devastating neurological disease and due to no proper research strategy existing to create treatments.

The research colloquiums are also made available to invited researchers for free or at a much reduced cost in order to encourage research and international collaboration.

The charity continues to feel that better education of healthcare staff is the key to improving conditions for people with ME and their families. liMER aims to provide all our work for free or at cost price.

We are an independent charity whose focus is on better education, better awareness and a strategy of high-quality biomedical research into myalgic encephalomyelitis.

We hope to continue to find, fund and facilitate research and provide a means for patient groups to raise more awareness of this disease – ME – and so enable a rapid resolution to be created by provision of treatments and cures from high-quality science.

Section F

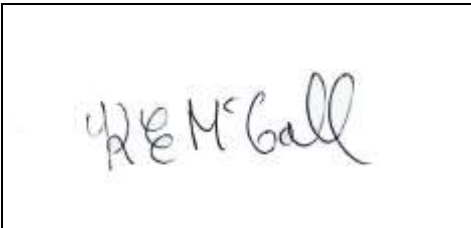

Other optional information

Section G

Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Kathleen McCall	Richard Simpson
Position (eg Secretary, Chair, etc)	Chair	Trustee
Date	29 th June 2020	28 th June 2021



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name	INVEST in ME RESEARCH	No (if any)	1153730
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Receipts and payments accounts

CC16a

For the period from	Period start date	To	Period end date
	01-Oct-19		30-Sep-20

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
General Donation , Legacies and Grants	52,672	-	-	52,672	191,676
Conferences and meetings	7,443	-	-	7,443	19,704
Printed material (guidelines, booklets, brochures, cards, journals etc)	242	-	-	242	1,610
Tax refund / Gift Aid	650	-	-	650	1,261
Fund-raising Charity Activities	-	-	-	-	7
Bank a/c Interest	19	-	-	19	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	61,026	-	-	61,026	214,258
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	61,026	-	-	61,026	214,258
A3 Payments					
Meetings and conferences	13,448	-	-	13,448	1,029
Printing of Brochures, Books & Guidelines	-	-	-	-	194
Postage, Packaging, Stationery	95	-	-	95	70
Governance, Web Services, Advertising	193	-	-	193	171
Fundraising Products/Equipment	46	-	-	46	1,737
Biomedical Research	217,797	-	-	217,797	-
Bank Charges	376	-	-	376	811
	-	-	-	-	-
	-	-	-	-	-
Sub total	231,956	-	-	231,956	4,012
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	231,956	-	-	231,956	4,012
Net of receipts/(payments)	- 170,930	-	-	- 170,930	210,246
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	343,684	-	-	343,684	-
Cash funds this year end	172,754	-	-	172,754	210,246

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Lloyds	172,754	-	-
		-	-	-
		-	-	-
	Total cash funds	172,754	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
<i>K. McCall</i>	Kathleen McCall	27/06/2021
<i>Richard Simpson</i>	Richard Simpson	27/06/2021



Section A

Independent Examiner's Report

**Report to the trustees/
members of**

INVEST in ME RESEARCH

**On accounts for the year
ended**

30th September 2020

**Charity no
(if any)**

1153730

Set out on pages

1 and 2

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 30/09/2020.

**Responsibilities and
basis of report**

As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

**Independent
examiner's statement**

I have completed my examination. I confirm that no material matters have come to my attention (other than that disclosed below *) in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

** Please delete the words in the brackets if they do not apply.*

Signed:

Date:

2/7/2021

Name:

Paul Booth

**Relevant professional
qualification(s) or body
(if any):**

Address:

30 Provene Gardens

Waltham Chase

S032 2LE

Only complete if the examiner needs to highlight matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.