



# Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	01	10	2021		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 <b>may choose</b> to include additional information, where relevant, about:</p> <ul style="list-style-type: none"><li>• policies and procedures adopted for the induction and training of trustees;</li><li>• the charity's organisational structure and any wider network with which the charity works;</li><li>• relationship with any related parties;</li><li>• trustees' consideration of major risks and the system and procedures to manage them.</li></ul>	<p>Invest in ME Research (liMER) 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

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.

**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)**

<p>The main activities are–</p> <p>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.</p> <p>Organisation of international research colloquiums to encourage new collaborative and cooperative possibilities for research into ME.</p> <p>Creation and development of network of young researchers for ME.</p> <p>Foundation and support of a collaborative European ME Research Group network for researchers to come together.</p> <p>Foundation and support of a collaborative European ME Clinicians Council network for European clinicians to come together to build knowledge and expertise around ME.</p> <p>Production of educational material (videos, booklets, journals and guidelines) related to ME.</p> <p>Finding, facilitating and funding of biomedical research into ME.</p> <p>Continuing development of the Centre of Excellence for ME model that the charity has proposed and championed since 2011.</p> <p>Initiation of awareness and fund-raising activities regarding ME.</p> <p>Maintenance of web sites for the charity, and European ME organisations containing educational information regarding ME and our initiatives and conferences</p> <p>Creation and administering of webinars to enhance education of the public and to disseminate information around Europe regarding ME.</p> <p>Advocacy work to help patients in need.</p> <p>Distribution of regular newsletters to patient groups, patients, healthcare staff, media, politicians and general public regarding ME.</p> <p>Chairing the European ME Alliance and participating in European collaborative projects regarding awareness of ME.</p>
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**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 arrange 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 on 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**

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



CHARITY COMMISSION  
FOR ENGLAND AND WALES

Charity Name	No (if any)
INVESTin ME RESEARCH	1153730

## Receipts and payments accounts

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For the period from	Period start date 01-Oct-21	To	Period end date 30-Sep-22
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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 £
<b>A1 Receipts</b>					
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	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>363,811</b>	<b>-</b>	<b>-</b>	<b>363,811</b>	<b>161,990</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>363,811</b>	<b>-</b>	<b>-</b>	<b>363,811</b>	<b>161,990</b>
<b>A3 Payments</b>					
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
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>21,228</b>	<b>-</b>	<b>-</b>	<b>21,228</b>	<b>208,529</b>
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>21,228</b>	<b>-</b>	<b>-</b>	<b>21,228</b>	<b>208,529</b>
<b>Net of receipts/(payments)</b>	<b>342,583</b>	<b>-</b>	<b>-</b>	<b>342,583</b>	<b>- 46,539</b>
<b>A5 Transfers between funds</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>A6 Cash funds last year end</b>	<b>126,215</b>	<b>-</b>	<b>-</b>	<b>126,215</b>	<b>-</b>
<b>Cash funds this year end</b>	<b>468,798</b>	<b>-</b>	<b>-</b>	<b>468,798</b>	<b>- 46,539</b>

## 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 £
<b>B1 Cash funds</b>	Lloyds	468,798	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	468,798	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
<b>B2 Other monetary assets</b>	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<b>B3 Investment assets</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
<b>B4 Assets retained for the charity's own use</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B5 Liabilities</b>	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	21/06/2023	
	<i>Richard Simpson</i>	Richard Simpson	21/06/2023	



# CHARITY COMMISSION FOR ENGLAND AND WALES

## Independent examiner's report on the accounts

### Section A

### Independent Examiner's Report

Report to the trustees/  
members of

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 PROVENGE GARDENS  
SOUTHAMPTON  
SO3A 2LE