



# Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	01	10	2020		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				
9				
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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>liMER 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>
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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>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>Organisation of annual public International ME Conferences that attract doctors, scientists, researchers, patients and carers from around the world.</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>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 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 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

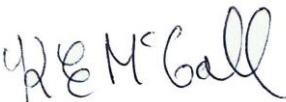

## Other optional information

Section G

Declaration

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

Signed on behalf of the charity’s trustees

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



CHARITY COMMISSION  
FOR ENGLAND AND WALES

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

## Receipts and payments accounts

CC16a

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 £
<b>A1 Receipts</b>					
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
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	161,990	-	-	161,990	61,026
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	-	-	-	-	-
<b>Total receipts</b>	161,990	-	-	161,990	61,026
<b>A3 Payments</b>					
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
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	208,529	-	-	208,529	231,956
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	-	-	-	-	-
<b>Total payments</b>	208,529	-	-	208,529	231,956
<b>Net of receipts/(payments)</b>	- 46,539	-	-	- 46,539	- 170,930
<b>A5 Transfers between funds</b>	-	-	-	-	-
<b>A6 Cash funds last year end</b>	172,754	-	-	172,754	-
<b>Cash funds this year end</b>	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 £
<b>B1 Cash funds</b>	Lloyds	126,215	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	<b>126,215</b>	<b>-</b>	<b>-</b>
	(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	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.**