



Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	01	10	2019		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				
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)

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

- 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.

Invest in ME Research (IIMER) works to build relationships nationally and internationally with other organisations who promote similar aims.

In particular, IIMER has continued to chair the European ME Alliance, a collaboration of national patient organisations and charities across Europe.

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.

Our objectives are to facilitate high-quality biomedical research into ME with international collaboration.

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.</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>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 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

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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

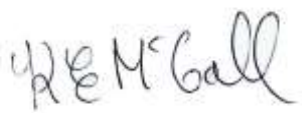

Other optional information

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