

# **Trustees' Annual Report for the period**

Period end date Period start date 2022 08 2021 March Jan From To

# Section A

# Reference and administration details

BACME British Association of Clinicians in ME/CFS (BACME) **Charity name** 

Other names charity is known by

BACME British Association for CFS/ME (BACME)

Registered charity number (if any) 1193035

Charity's principal address

TRACCS, Paediatric and Adolescent Department, University College Hospital London, 6th floor central, 250 Euston road, London **NW1 2PG Postcode** 

#### 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	Mrs Karen Anna Gregorowski	Chair		BACME AGM
2	Mrs Christine Mary Oliver	Deputy Chair & Treasurer		BACME AGM
3	Ms Deborah Karen Roberts	Board Secretary & Research executive		BACME AGM
4	Dr Victoria Louise McKeever	Information and communication executive		BACME AGM
5	Mrs Kirsty Northcott	Training & Education executive		BACME AGM
6	Mrs Ceridwen Rutter	Patient & Public Involvement executive		BACME AGM
7	Mrs Beverly Knopps	Non-executive Trustee		BACME AGM
8	Mrs Charlotte Joanna Adler	Non-executive Trustee		BACME AGM
9	Miss Rhonda Valerie Knight	Non-executive Trustee (PPI)		BACME AGM
10	Mr Les Parry	Non-executive Trustee (PPI)		BACME AGM
11	Dr Marta Prytys	Non-executive Trustee		BACME AGM
12	Mrs Katie Street	Non-executive Trustee		BACME AGM
13	Dr Peter Gladwell	Non-executive Trustee		BACME AGM
14	Mrs Deborah Gardner	Non-executive Trustee		Appointed by formal election at AGM on 28th Jan 2021

# Section B Structure, governance and management

#### Description of the charity's trusts

#### Type of governing document

(eg. trust deed, constitution)

#### **BACME Constitution**



BACME CIO Constitution Jan 2022

# How the charity is constituted

(eg. trust, association, company)

#### BACME is an association

#### Trustee selection methods

(eg. appointed by, elected by

Trustees are appointed by an election process conducted at AGM and in accordance with the BACME constitution.

The following conditions are cited at section 12.2 of the BACME constitution:

- Charity trustees must be a member of a professional body relevant to their professional role and deliver or support clinical care to people with ME/CFS. In the case of patient representatives, Trustees must have direct personal experience of the condition, either as a patient or carer and be affiliated with a chronic fatigue syndrome (ME/CFS) service delivering care in line with BACME objects.
- Charity trustees agree to uphold and support the BACME constitution.
- Charity Trustees must hold current BACME membership and have been a BACME member for a minimum of 6 months prior to becoming a trustee

#### 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.

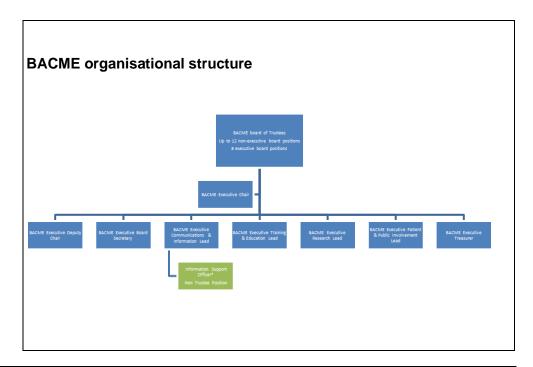
The Trustee training presentation link below has been used to prepare Trustees for CIO status which was awarded by the Charity commission on the 8<sup>th</sup> January 2021

https://e1.pcloud.link/publink/show?code=XZA1WmZhA5wqjnOLs0xi O0orU8tDkG6W1dV

Further in-depth trustee training has been delivered at a Board away day September 2021 and further training and development is planned for the forthcoming year

#### **BACME** conflict of interest policy

https://e1.pcloud.link/publink/show?code=XZm1WmZ3SN3D1olKv4E7K6v0ShwQS1wVrrk



## **Section C**

# Objectives and activities

The following is an extract from BACME constitution section 3:

The relief of sickness for the public benefit by:

- 3.1 Championing clinically effective practice in treating ME/CFS and other primary fatigue conditions
- 3.2 Disseminating of recent evidence and practice to clinical practitioners
- 3.3 Providing education and training for members respecting up-to-date evidence and best shared practice
- 3.4 Advocating for equity of access and excellence in the provision of services
- 3.5 Facilitating networking amongst clinicians, researchers and patients
- 3.6 Advocating for and promoting relevant research and to publish all useful results arising from any research supported

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

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)

BACME carries out its purposes for the public benefit and the relief of sickness through board meetings, educational webinars, maintaining an up-to-date website, an annual conference, regular newsletters and collaboration with relevant organisations and patient groups.

BACME membership is open to clinical professionals who are actively involved in providing or supporting an ME/CFS service which provides health care to members of the public who have ME/CFS.

BACME training events are primarily tailored for its membership.

Conference is open to non-members who are professionals working in the field of ME/CFS. BACME provides a clear public benefit; the relief of sickness by supporting BACME members to deliver up to date, clinically

effective treatment in the field of ME/CFS which reduces sickness by improving outcomes, quality of life and experiences for this patient group.

All trustees have signed the statutory declaration regarding guidance issued by the charity commission on public benefit.

## Section D

# Achievements and performance

# Summary of the main achievements of the charity during the year

The attached presentations have been delivered at the AGM on the 28<sup>th</sup> Jan 2021 and 2<sup>nd</sup> Feb 2022 and include a summaries of the main achievements of BACME during the year

https://e1.pcloud.link/publink/show?code=XZhDWmZ1HERVpmxMwpGjm0lDnfqnSlolED7

https://e1.pcloud.link/publink/show?code=XZQDWmZSvDr5ihH8W8GOp Mu6xfgAykdakUV

Summary of BACME key achievements and performance relating to BACME objectives in the relief of sickness for the public benefit.

#### 1. Championing clinically effective practice

- Post viral fatigue management guide
- BACME position paper- Dysregulation model
- Virtual conference May 2021
- Collated response to draft NICE ME/CFS guideline
- Webinar "A conversation about Long Covid"
- Successful Lottery Community fund grant 10k for new BACME website Jan 22

#### 2. Dissemination of recent evidence & practice

- Peer Supervision & topic-based webinars
- Dissemination of BACME position paper
- Newsletters & Communications with BACME members
- Dissemination of NICE response to members
- Virtual conference May 2021

#### 3. Provision of education & training

- Peer review & topic-based webinars
- Newsletters & communications
- Virtual conference May 2021

#### 4. Advocating for equity & excellence

- All BACME activities
- Becoming a Charitable Incorporated Organisation

#### 5. Facilitating networking

- Webinars
- BACME Executive members attending CMRC conference
- Virtual conference May 2021
- **6.** BACME Chair is a CMRC Associate Board member

#### 7. Advocate, promote and disseminate research

- Newsletters & Communications

#### **Chairs report**

It is with great pleasure and pride that I am writing this report as BACME Chair to share what we have collectively achieved and the ways we met

# Achievements and performance

our overall objective of the relief of sickness during 2021. The BACME Board works as a remarkable team, each Executive member and Trustee bringing unique skills and strengths to the table while recognising and respecting each other's talents and showing kindness to each other. It is not surprising to me that the work of BACME continued and transformed during this time of global uncertainty and BACME met all key objectives. Our first aim of relieving sickness by championing clinically effective practice in treating ME/CFS and other primary fatigue conditions including long covid has been met as follows: in response to the pandemic, BACME, in collaboration with the York fatigue service, published a post viral fatigue guideline intended for use by all affected by post viral fatigue and professionals working in this field, many thanks to Dr Vikki McKeever, Executive Communication and Information Lead, for facilitating this work; the BACME Board held a number of extraordinary meetings to agree a position paper on key evidence based treatments for ME/CFS, thank you for to all Executive Team members and trustees involved in this process; BACME delivered webinars on significant and relevant topics including Virtual working with individual patients and groups during the Covid period and on Dysregulation theory and translating this into practice, many thanks to Kirsty Northcott, Executive Training and Education Lead for ensuring a continued programme of relevant and timely Education and peer supervision webinars; in December 2020 BACME submitted an extensive, collaborative response regarding the draft NICE ME/CFS guideline, many thanks to the NICE response team, thank you again to Vikki, Deb Roberts BACME Executive Board Secretary and Research lead, Ceri Rutter Patient and Public Involvement Lead working with Rhonda Knight and Les Parry, to Trustee Dr Pete Gladwell, and all who gave their time to assist with the completion of this response. We received many thanks from members for doing this.

Dissemination of recent evidence and practice occurred through regular peer supervision, topic-based education webinars, the dissemination of a position paper, our first and very successful virtual conference May 2021 and regular newsletters and key messages sent to members during the year. Vikki works extremely hard and seemingly tirelessly to ensure timely and pertinent communication with members while Deb working with Rhonda and Emily Tims ensure newsletters are high quality, evidence based and sent out at regular intervals. Collating and disseminating the position paper, a BACME Board team effort, ensured being up to date with most recent relevant research as did the collation of a high-quality NICE response representative of members and services. Thank you to many BACME members for providing material for this response.

We continued to advocate for equity of access and excellence in the provision of ME/CFS services in 2021. Becoming a Charitable Incorporated Organisation on January the 8<sup>th</sup> 2021 will ensure we can work with services at a more strategic level in more and effective ways. While this is a team achievement, it would not have happened without the determination and attention to detail provided by BACME Executive Deputy Chair and Finance Lead, Christine Oliver. Thank you very much for continuing to keep focussed on this goal when other Executive members were working on the position paper, NICE response, and webinars. Christine has an extraordinary capacity for multitasking and seemingly boundless energy, a very good combination for excellent outcomes.

We were delighted to be awarded a lottery community fund grant of £10,000 in January 2022 which has been put to excellent use in the procurement and design of a new BACME website. This website will

#### Section D

# Achievements and performance

facilitate all BACME's key objectives through a modern and intuitive new platform.

Regular peer supervision webinars provided the vehicle for on-going facilitation of networking amongst clinicians.

In October 2021 the BACME board held their first board development day Face to Face in Birmingham. At this event, the decision to change BACME organisational name from "The British Association of CFS/ME" (BACME) to "The British Association of Clinicians in ME/CFS" (BACME) was agreed to better reflect our charitable purpose, membership and in line with the recently published NICE Guidance (NG206). As BACME Chair, I continue to be part of the MERC, allowing for collaboration between organisations. Executive Research Lead, Deb Roberts ensured that we continue to advocate for and publish all useful results arising from research supported by BACME, through publication in BACME bulletin. Throughout this past year we have been lucky to have three patient / carer representatives involved in each outcome achieved by BACME Board, many thanks to Ceri Rutter, Rhonda Knight and Les Parry for the experience, insight, and wisdom you bring to BACME Board, this is most valuable.

Many thanks too to the quieter members of BACME Board who have worked in the background picking up essential tasks whenever required, Charlie Adler, Bev Knopps, Katie Street, Peter Gladwell, Debbie Gardner, Les Parry, Marta Prytys and Jayne Woodcock. A big thank you too to Harpinder Aujla, information support officer working with Vikki. Pinda has been instrumental in looking after membership information and the BACME website, working with Vikki and Christine.

Overall, this has been an excellent year for BACME with an increase in membership, participation, and engagement. BACME has been approached by a number of organisations to explore increased collaboration. We look forward to another productive year in 2022/3. Next steps include the launch of our new website in September 2022 and virtual conference in November 2022, updating and producing new guidance to further support members, ensuring an on-going programme of webinars and similar educational events, forming young people's and severely affected advisory groups and another year of what we hope will be increased membership, paying particular attention to less represented professional groupings while keeping patients, carers, and representatives at the heart of all we do.

BACME Chair Anna Gregorowski

# **Section E**

# **Financial review**

# Brief statement of the charity's policy on reserves

The charity aims to maintain reserves for the following.

Contingency fund reserve £8000

Details of any funds materially in deficit

The BACME account is not in deficit and continues to generate a small but healthy profit.

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.

**Section F** 

BACME hold no material assets in terms of buildings, IT hardware or any type of equipment.

BACME does not pay any person on the board of trustees. All positions held are delivered on a voluntary basis or as a very small proportion of their professional roles.

Our 2020 conference had to be cancelled due to COVID -19 and the £9195 conference fees received have either been refunded or held over for attendance at BACME's virtual conference in May 2021.

BACME's main income is from membership fees and main expense is maintenance and development of BACME's website currently provided by Circle. However, the recent lottery community fund award of £10,000 will be used to procure and design a new BACME website.

BACME's May 2021 virtual conference generated a profit of £6000 for reinvestment in BACME activities for the relief of sickness for public benefit.

BACME have not increased membership fees for several years and an increase of £5 on our membership fees would increase income by around £1000 per year. This is planned for September 2022 when the new BACME website is expected to go live.

Increasing BACME membership by 20% would increase income at current rates by around £800 per year. It is hoped that this will be achieved by raising the profile of BACME and communicating all the benefits that BACME has to offer. The more professionals in the field of ME/CFS BACME can reach, the better able we will be to deliver BACME purpose of "the relief of sickness" for patients with ME/CFS.

BACME is led and delivered by professionals in the field of ME/CFS on a voluntary basis with some executive trustees having a few hours a week of their professional roles dedicated to this. Considering any income generation initiatives for the benefit of BACME members and the delivery of its purpose, needs to be considered carefully in the light of this. Thought will need to be given with regards to paying for services such as webinar speakers and administrative support. Members' views would be

very welcome on this dialogue as we move forward as an organisation.

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Other optional information

**TAR** 7 March **2012** 

Section G Declaration

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

Signed on behalf of the charity's trustees

Signature(s)	Anna angu		2 Ciril	
Full name(s)	NNA GREGOROWSKI	СН	RISTINE MARY OLIVER	
Position (eg Secretary, Chair etc			BACME DEPUTY CHAIR & TREASURER	•
Dat	е			
	19/01/2023			



Charity Name No (if any)
British Association of Clinicians in ME/CFS 1193035

# Receipts and payments accounts

 For the period from
 Period start date
 To
 Period end date

 31/03/2022
 31/03/2022

CC16a

Section A Receipts and	d payments				
	Unrestricted funds	Restricted funds	Endow ment funds	Total funds	Last year
	to the nearest	to the nearest £			
A1 Receipts					
Balance Brought Forward	15,788	-	-	15,788	-
Member Subscriptions	6,509	-	-	6,509	-
Cheque Donation	103	-	-	103	-
Lottery Grant	10,000	-	-	10,000	-
Expenses Repaid	111	-	-	111	-
Tickets sold for Conference	6,625	-	-	6,625	-
	,	-	-	-	-
	-	-	-	-	-
<b>Sub total</b> (Gross income for AR)	39,136	-	-	39,136	-
A2 Asset and investment sales, (see table).					
(000 100.0).	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	39,136	-	-	39,136	
·					
A3 Payments					
Website Costs	4,653	-	-	4,653	-
Membership Refund	25	-	-	25	-
Meetings Expenses	3,632	-	-	3,632	-
Conference Refunds	120	-	-	120	-
Misc	184	-	-	184	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	8,614	-	-	8,614	-
A4 Asset and investment					
purchases, (see table)					
pureriaces, (000 table)	-	_	_	_	
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	8,614	-	-	8,614	
Net of receipts/(payments)	30,522			30,522	
	30,322	_	-		
A5 Transfers between funds	-	-	-	-	
A6 Cash funds last year end	-	-	-	-	
Cash funds this year end	30,522	_	_	30,522	

Section B Statement	of assets and liabilities		he period	
		Unrestricted	Restricted	Endow ment
Categories	Details	funds	funds	funds
B1 Cash funds	Total cash funds	to nearest £	to nearest £	to nearest £
Di Casiliulius		30,522	-	-
		-	-	-
		-	-	-
	Total cash fund	30,522	-	-
	(agree balances with receipts and paymer	ts		
	account(s		OK Restricted	OK Endow ment
		Unrestricted funds	funds	funds
	Details	to nearest £	to nearest £	to nearest £
B2 Other monetary assets	Details	-	-	-
		-	_	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		Fund to which	Cost (optional)	Current value
	Details	asset belongs		(optional)
33 Investment assets			-	-
			-	-
			-	-
			-	-
			-	_
			-	
		Fund to which		Current value
	Details	asset belongs	Cost (optional)	(optional)
B4 Assets retained for the			-	-
charity's own use			-	-
			_	-
			-	-
			-	-
			-	-
			-	-
			-	-
			_	-
		Fund to which	Amount due	When due
	Details	liability relates	(optional)	(optional)
35 Liabilities			-	
			-	
			-	
			-	
			-	
			-	
Diamod by one setting to office				D. C.
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name  ANNA GREGOROWSKI  CHRISTINE MARY OLIVER		Date of approval
	Signature  Ana Angh			арріочаі
	ahra Gran			19/01/2023