

# Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	29	09	2023		31	05	2024

## Section A Reference and administration details

Charity name

CHAMP1 UK

Other names charity is known by

Registered charity number (if any)

1204985

Charity's principal address

CHAMP1 UK, 77 Hardy Crescent

Wimborne

Dorset

Postcode BH212AR

### 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	Scott Robin Hutchings			
2	Sarah Ruth Hutchings			
3	Jeffrey Dean D'Angelo			
4	Lorna Rose Blacklidge		12/03/2024 onwards	
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6				
7				
8				
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10				
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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)	Constitution
How the charity is constituted (eg. trust, association, company)	CIO - FOUNDATION
Trustee selection methods (eg. appointed by, elected by)	Elected by board members

### 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.

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## Section C Objectives and activities

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

The improvement of the lives of those affected by CHAMP1 disorders.  
To advance clinical research, effective treatment and early detection.  
To increase public awareness.  
To provide family support and patient advocacy.

**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)**

In accordance with its charitable objectives, CHAMP1 UK has continued to support individuals and families affected by CHAMP1-related disorders by providing information, advocacy, and a supportive community. The charity has worked to raise awareness among medical professionals, researchers, and the wider public to improve diagnosis, treatment, and understanding of this rare genetic condition.

Over the past year, CHAMP1 UK has undertaken the following key activities for public benefit:

- **Support and Community Building:** Facilitating connections between families through online forums, support groups, and events, ensuring that those affected by CHAMP1 do not face their journey alone.
- **Raising Awareness:** Engaging in awareness campaigns, and participating in medical conferences, and genetic events.
- **Research and Advocacy:** Exploring opportunities for scientific research into CHAMP1, advocating for greater understanding of the condition, and working with researchers to advance potential treatments.
- **Educational Resources:** Developing and distributing materials for families, caregivers, and professionals.
- **Fundraising Initiatives:** Organising events and campaigns to secure funding for research, support services, and awareness programmes.

The trustees confirm that they have had due regard to the Charity Commission's guidance on public benefit when reviewing the charity's aims and objectives and in planning its activities. Every initiative undertaken by CHAMP1 UK has been designed to provide direct and meaningful benefits to those affected by CHAMP1 and to contribute to the wider understanding of the rare genetic disorder.

**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.

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

As CHAMP1 UK's founding year, it has been a pivotal period of growth, community building, and awareness-raising. The charity has made significant progress in supporting families, increasing awareness of CHAMP1, engaging with the medical community, and laying the groundwork for future expansion.

#### **Support & Community**

CHAMP1 UK has successfully arranged several family meet-ups throughout the year, providing vital opportunities for connection and shared experiences among families affected by CHAMP1. Additionally, the charity played a key role in organising the global CHAMP1 conference in Orlando, bringing together experts, researchers, and families to advance understanding of the condition.

The charity has continued to expand its online presence, ensuring that newly diagnosed families can easily access support and guidance. A number of new families have reached out this year, and CHAMP1 UK has provided them with crucial support during their life-changing diagnosis.

#### **Awareness & Advocacy**

CHAMP1 UK has led impactful awareness campaigns, particularly for CHAMP1 Awareness Day. The charity successfully arranged for UK landmarks to be illuminated in purple and secured coverage in newspapers and on BBC radio, increasing public knowledge of the condition.

Through engagement with local newspapers, magazines, and radio stations, CHAMP1 UK has amplified its reach and provided a platform for families to share their experiences. The charity has also collaborated with key organisations, including the CHAMP1 Research Foundation and CHAMP1 Research Foundation - EU, strengthening international advocacy efforts.

#### **Research & Medical Engagement**

While CHAMP1 UK has not directly funded research projects this year, it has played an essential role in facilitating family participation in research studies. The charity has actively reached out to researchers and universities, ensuring that CHAMP1 is included in new scientific studies to expand knowledge of the condition. Work is also ongoing to improve and create CHAMP1-related educational materials and medical resources.

#### **Educational Resources & Outreach**

The charity has developed new materials, including website content and promotional resources, to educate families, professionals, and the wider public about CHAMP1. Participation in conferences, training courses, and events has further solidified CHAMP1 UK's role as an advocate for those affected by the condition.

Additionally, the charity has begun engaging with local schools to raise awareness and provide relevant information, ensuring that children with CHAMP1 receive better-informed support within educational settings.

#### **Fundraising & Financial Growth**

As its first year as a registered charity, CHAMP1 UK has successfully raised over £2,500 through various fundraising initiatives, including raffles and a plane pull event. This achievement lays a strong foundation for future financial growth, although securing grants, sponsorships, and corporate partnerships remains an area for future development.

#### **Impact & Growth**

Since its inception, CHAMP1 UK has grown significantly, establishing itself as a key resource for families affected by CHAMP1 in the UK. One new family shared a powerful testimonial:

*"You've made me feel better about this CHAMP1 diagnosis in 20 minutes than all the doctors have in the last two months."*

While this year has been focused on building a strong foundation, the progress made in community support, awareness, and research engagement has set the stage for continued impact and expansion in the years to come.

## Section E

## Financial review

### Brief statement of the charity's policy on reserves

CHAMP1 UK aims to maintain a level of reserves that ensures financial stability and allows the charity to continue its work in supporting families, raising awareness, and facilitating research. As this is our founding year, our current focus is on building sustainable income streams to support future activities.

The trustees will regularly review the reserves policy to ensure that funds are managed responsibly and in line with the charity's objectives, with the aim of establishing a designated reserve fund to cover operational costs and unforeseen expenses.

### Details of any funds materially in deficit

N/A

### 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


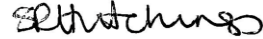
## Other optional information

## 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)	Scott Robin Hutchings	Sarah Ruth Hutchings
Position (eg Secretary, Chair, etc)	Chair	Board member
Date	06/03/2025	



CHARITY COMMISSION  
FOR ENGLAND AND WALES

Charity Name  
CHAMP1 UK

No (if any)  
1204985

## Receipts and payments accounts

CC16a

For the period  
from

Period start date  
29/09/2023


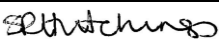
To

Period end date  
31/05/2024

### 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>					
Donations and legacies	£2,134	-	-	2,134	-
Other trading activities	£484	-	-	484	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>2,618</b>	<b>-</b>	<b>-</b>	<b>2,618</b>	<b>-</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>2,618</b>	<b>-</b>	<b>-</b>	<b>2,618</b>	<b>-</b>
<b>A3 Payments</b>					
Generating Funds	300	-	-	300	-
Charitable Activities	353	-	-	353	-
Support Costs	382	-	-	382	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>1,034</b>	<b>-</b>	<b>-</b>	<b>1,034</b>	<b>-</b>
<b>A4 Asset and investment purchases, (see table)</b>					
Purchase of Assets	1,343	-	-	1,343	-
	-	-	-	-	-
<b>Sub total</b>	<b>1,343</b>	<b>-</b>	<b>-</b>	<b>1,343</b>	<b>-</b>
<b>Total payments</b>	<b>2,377</b>	<b>-</b>	<b>-</b>	<b>2,377</b>	<b>-</b>
<b>Net of receipts/(payments)</b>	<b>241</b>	<b>-</b>	<b>-</b>	<b>241</b>	<b>-</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>376</b>	<b>-</b>	<b>-</b>	<b>376</b>	<b>-</b>
<b>Cash funds this year end</b>	<b>617</b>	<b>-</b>	<b>-</b>	<b>617</b>	<b>-</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>	General Funds	617	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	<b>617</b>	<b>-</b>	<b>-</b>
	(agree balances with receipts and payments account(s))	OK	OK	OK
<b>B2 Other monetary assets</b>	Details			
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<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)
	Computers & other IT equipment		-	600
	Gazebo & event material		-	300
	Branded clothing		-	100
	Promotional Material		-	100
			-	-
			-	-
			-	-
			-	-
			-	-
<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	
		Scott Hutchings	06/03/2025	
		Sarah Hutchings	06/03/2025	