

CRELD1 WARRIORS

England & Wales · Charity number 1209106

Details

Status Registered

Legal form CIO

Registered 2024-07-12

Register [View on the Charity Commission register](#)

Contact

Address 159 Reading Road South
Church Crookham
Fleet
GU52 6AQ

Phone 07508542562

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Website CRELD1.com

Activities

Objects: TO RELIEVE THE NEEDS OF CHILDREN WITH CRELD1 GENE SEQUENCE VARIATION AND RELATED DISORDERS AND THEIR FAMILIES THROUGH: A) PROVIDING SUPPORT FOR FAMILIES CARING FOR A CHILD WITH THIS CONDITION;B) INCREASING THE UNDERSTANDING OF THE PUBLIC ON THIS SUBJECT;C) MAKING GRANTS TO SUPPORT RESEARCH FOR SUCH PURPOSES;D) SUCH WAYS AS THE TRUSTEES MAY DETERMINE.IN THESE OBJECTS 'CRELD1' (CYSTEINE RICH WITH EGF LIKE DOMAINS 1) IS A PROTEIN CODING GENE. SEQUENCE CHANGES IN THE CRELD1 GENE ARE TYPICALLY ASSOCIATED WITH THE CAUSE OF ATRIOVENTRICULAR SEPTAL DEFECT (AVSD).

Activities: To provide support for families caring for a child with CRELD1, to raise awareness of this very rare disease and to support medical research.

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities, The General Public/mankind

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-04-05	£104,922	£10,000	-	-

Trustees

Name	Role	Appointed
Jessica Clatworthy	Chair	2024-07-12
Adam Neal Clatworthy		2024-07-12
Emma Jayne Court		2024-07-12
Kate Edwards		2024-07-12
Oliver Michael Folliot Powell		2025-02-24
Samantha Lusty		2024-07-12
WILLIAM MARCUS CHRISTOPHER CAMPBELL		2024-07-12

Accounts



CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' Annual Report for the period

From 13 July 2024
Period end date

Period start date To 05 April 2025

Charity name: CRELD1 Warriors

Charity registration number: 1209106

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	As a registered UK charity, our mission is to provide support for families caring for a child with CRELD1 gene mutations, to raise awareness of this extremely rare disease and to support vital medical research to help us find an effective treatment.
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	Families Support/Information Services The charity provides a support group for individuals and families affected by the CRELD1 condition. We aim to provide the latest information on the condition to families and health professionals via our website and social media. Educational Activities We continue to work on raising both public awareness and education amongst key medical professionals throughout the world, so they can better understand the signs, symptoms and medical diagnosis of CRELD1. Speaking at medical and scientific conferences provides opportunities to fulfil our aims and objectives whilst developing strategic partnerships with research facilities, medical and pharmaceutical institutions, and like-minded charitable bodies. Research

		The charity has raised funds to pay for research to be undertaken at The University of Birmingham. We are also funding a project with Unravel Biosciences, which uses AI technology and nasal swabs from patients with CRELD1 to find alternative treatments targeted at the gene. We have to fund the second half of this project in 2026.
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	The Trustees consider the charity's activities are wholly in the public interest and designed to benefit all those who suffer from CRELD1, their families and medical professionals dealing with this debilitating condition, in line with the Charity's Commission guidance on 'public benefit'

Achievements and Performance

	SORP reference	
Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.	Para 1.20	The charity has been extremely successful in its first year. We were able to start with some small fundraising events, such as a Great South Run and a sing-a-long hosted by one of our trustees. In December 2024, one of our parents - Oli Powell - who has a child with CRELD1, took on an incredible challenge of running 7 marathons in 7 days. He raised approx £100,000 for the charity, and also raised awareness with media coverage, featuring on BBC Radio Berkshire, The Daily Mail, Mail on Sunday, and BBC Breakfast News. https://www.dailymail.co.uk/health/article-14189645/boy-disease-rare-27-people-diagnosed.html 

		We have been able to fund the start of a project with Dr Felix Chan at The University of Birmingham, with £20,000 to be donated to his project (currently donated £10,000) to begin his work collecting skin biopsies and creating a cell model. We are also looking to invest in a project with unravel biosciences (https://www.unravel.bio/), where we have collected nasal swabs from 17 patients around the world with CRELD1, and they will use an AI database to find therapeutics more targeted to this gene. We have funded half this project, with the second half due in 2026. Further funding to test safety of use of any therapeutics with this gene will likely also be needed. We hope to fund further research and find a treatment that is more effective at managing this condition, or even a gene therapy.
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Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	
Performance of fundraising activities against objectives set	Para 1.41	
Investment performance against objectives	Para 1.41	

Other		
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Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	Thanks to the great support from family and friends, and other CRELD1 families, the charity is in a great position with £94,922 in funds in the charity account. This is enough to cover our next stage of the project with Unravel Biosciences (£25,000). We also have many more upcoming fundraising events planned for the rest of 2025.
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	The purpose of the reserves is: To fund working capital and time lags in the receipt of promised funds. To fund unexpected expenditure, e.g., when projects overrun, or unplanned events occur. To manage economic or regulatory changes which may have unforeseen financial consequences. We assess the level of general reserve needed by looking forward and considering the risks to our funding balanced against our expenditure commitments. To ensure we can continue to operate in accordance with our plans, we would look to hold a general reserve in the range £10,000 - £12,000 to cover unfunded committed costs for the next 6 months.
Amount of reserves held	Para 1.22	As of April 2025 our reserves are £94,922
Reasons for holding zero reserves	Para 1.22	N/A
Details of fund materially in deficit	Para 1.24	N/A
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	Fundraising enough money to be able to make the impact we want to make. Access to grants is much harder than anticipated, but something we are working on.

Additional information (optional)

You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	We are 100% funded by donations and fundraising events.
Investment policy and objectives including any social investment policy adopted	Para 1.46	
A description of the principal risks facing the charity	Para 1.46	
Other		

Structure, Governance and Management

Description of charity's trusts:		
Type of governing document (trust deed, royal charter)	Para 1.25	CIO association constitution
How is the charity constituted? (e.g unincorporated association, CIO)	Para 1.25	CIO association constitution (formed July 2024)
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of	Para 1.25	By appointment of registered members at general meetings and by Trustee

any person or body entitled to appoint one or more trustees		
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Additional information (optional)

You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	New trustees are asked to abide by a Code of Conduct and are issued with Essential Information for Trustees from the Charities Commission, sign a Trustee Declaration and complete a Fit and Proper persons form.
The charity's organisational structure and any wider network with which the charity works	Para 1.51	CRELD1 is run on a voluntary basis. Trustees consult on all significant matters of policy formulation, family support and methods of communication about CRELD1 information services to medical professionals. The Scientific Advisory Board remains in place with 12 leading scientific advisors helping us understand the research and determine the most relevant use of funding. The charity operates the following policies: data, privacy, and accessibility.
Relationship with any related parties	Para 1.51	The charity is a member of: • Genetic Alliance UK • UK Rare Epilepsies Together network (UKRET) • Rare Epilepsy Network (REN)
Other		

Reference and Administrative details

Charity name	CRELD1 Warriors
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Other name the charity uses	
Registered charity number	1209106
Charity's principal address	159 Reading Road South, Fleet Hampshire GU52 6AQ

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	Jessica Clatworthy			Co-founder
	2	Adam Clatworthy			Co-founder
	3	Emma Court			
	4	Kate Edwards			
	5	Samantha Lusty			
	6	Will Campbell			

Corporate trustees – names of the directors at the date the report was approved

[illegible]

Name of trustees holding title to property belonging to the charity

[illegible]

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	

Additional information (optional)

Names and addresses of advisers (Optional information)

	Type of adviser	Name	Address
	Name of chief executive or names of senior staff members (Optional information)		

Exemptions from disclosure

Reason for non-disclosure of key personnel details

Other optional information

The CRELD1 Warriors Trustees would like to thank all their donors and volunteers for their support throughout the year. Special mention should go to our CRELD1 fundraising heroes during the period:

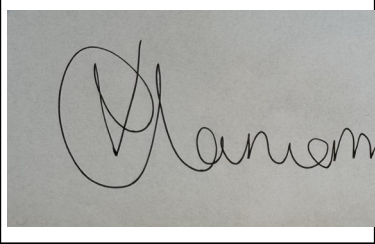
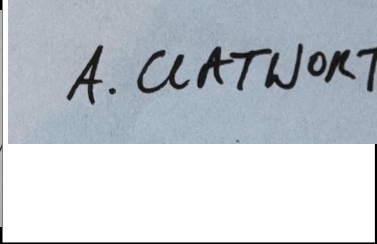
Oli Powell
Samantha Lusty
Kay White
The family of Barry Martin

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Declarations

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

Signed on behalf of the charity’s trustees

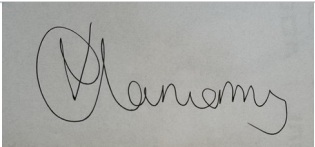
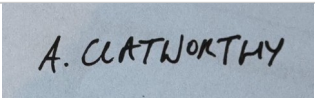
		Signature(s)		
		Full name(s)	J Clatworthy	A Clatworthy
		Position (eg Secretary, Chair, etc)	Chair	Trustee
		Date	14/12/2025	14/12/2025

	CRELD1 Warriors			No (if any)		
	Receipts and payments accounts				CC16a	
	For the period from	Period start date	To	Period end date		
		13/07/2025		05/04/2025		
Section A						
Receipts and payments						
	Unrestrict ed funds	Restrict ed funds	Endowme nt funds	Total funds	Last year	
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £	

A1 Receipts					
Donations	104,922	-	-	104,922	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total(Gross income for AR)	104,922	-	-	104,922	-
A2 Asset and investment sales, (see table).					
	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	104,922	-	-	104,922	-
A3 Payments					
Birmingham University	10,000	-	-	10,000	-
		-	-		-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	10,000	-	-	10,000	-

A4 Asset and investment purchases, (see table)						
	-	-	-	-		
	-	-	-	-		
Sub total	-	-	-	-		
Total payments	10,000	-	-	10,000	-	
Net of receipts/(payments)	94,922		-	94,922		
A5 Transfers between funds	-	-	-	-	-	
A6 Cash funds last year end	-	-	-	-	-	
Cash funds this year end	94,922	-	-	94,922		
Section B Statement of assets and liabilities at the end of the period						
Categories	Details		Unrestricted funds	Restricted funds	Endowment funds	
			to nearest £	to nearest £	to nearest £	
B1 Cash funds			-	-	-	
			-	-	-	
			-	-	-	

[illegible]

	Details	Fund to which liability relates	Amount due (optional)	When due (optional)	
B5 Liabilities	Unravel Biosciences	research study	25,141	01 July 2025	
			-		
			-		
			-		
			-		
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval		
		J Clatworthy	19/12/2025		
		A Clatworthy	19/12/2025		



CHARITY COMMISSION
FOR ENGLAND AND WALES

Independent examiner's report on the accounts

Section A

Independent Examiner's Report

Report to the trustees

Charity Name

CRELD1 Warriors

On accounts for the year ended

5th April 2025

Charity
no (if
any)

1209106

Set out on pages

1&2

(remember to include the page numbers of additional sheets)

Responsibilities and basis of report

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **05/04/2025**.

As the charity's trustees, 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 all 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 in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report 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:** 23/01/2026**Name:** Gemma Taylor**Relevant professional qualification(s) or body (if any):**

AAT level 2&3

Address:

43A Guildford Road West

Farnborough

GU14 6PS

Section B**Disclosure**

Only complete if the examiner needs to highlight material 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.**