

CF WARRIORS

England & Wales · Charity number 1178063

Details

Status Registered

Legal form CIO

Registered 2018-04-24

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

Contact

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Chorley
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Website www.cfwarriors.org.uk

Activities

Objects: FOR THE PUBLIC BENEFIT, THE RELIEF OF SICKNESS AND THE PRESERVATION OF HEALTH AMONG PEOPLE WITH CYSTIC FIBROSIS BY:A) PROVIDING GOODS AND/OR EQUIPMENT THAT CAN BE USED TO AID THE FITNESS AND HEALTH OF PEOPLE WITH CYSTIC FIBROSIS AND SUPPORT AND PRACTICAL ADVICE FOR CARRYING OUT APPROPRIATE FORMS OF EXERCISE;B) PROVIDING FUNDING FOR RESEARCH INTO CYSTIC FIBROSIS, IN PARTICULAR THE TREATMENT OF CYSTIC FIBROSIS AND THE EFFECTS OF EXERCISE ON PEOPLE WITH CYSTIC FIBROSIS.

Activities: The charity's main activities are:a) We provide Warrior Packs that contain goods and/or equipment that can be used to aid the fitness and health of people with cystic fibrosis; b) We fund research into cystic fibrosis, in particular the effects of exercise on people with cystic fibrosis and any treatments that can potentially aid recovery before, during and after exercise.

Classification

- **How:** Other Charitable Activities
- **What:** General Charitable Purposes, Disability
- **Who:** Children/young People, People With Disabilities

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31		-	-	-
2024-03-31	£79,979	£90,189	-	-
2023-03-31	£74,340	£67,408	-	-
2022-03-31	£42,306	£52,001	-	-
2021-03-31	£28,959	£77,931	-	-
2020-03-31	£106,763	£58,196	-	-

Trustees

Name	Role	Appointed
JOSH LLEWELLYN-JONES OBE	Chair	2018-04-24
Dr PAUL LANGMAID CBE		2018-04-24
James Alexander Gadd		2024-02-26
Stephen Doyle		2020-02-05

CF WARRIORS

England & Wales - Charity number 1178063

Accounts



WARRIORS

ANNUAL REPORT

2023/24

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INTRODUCTION

CF Warriors was founded to motivate, inspire and support children with cystic fibrosis on their journey to a longer, happier and healthier life. Our mission is to raise awareness of the benefits of sport and exercise to the CF community across the globe.

It's been a year of change for the charity with our CEO Mark Llewellyn-Jones stepping down from his position and Paul Floyd stepping down as Trustee.

Joshua Llewellyn-Jones our Founding Trustee and Chair, is now responsible for the day to day running of the charity, management of our events, our communications and our corporate relationships.

We're very fortunate to welcome James Gadd to the Board of Trustees. James brings with him a wealth of knowledge of corporate relationships and is a Senior Business Development Executive at RBC Brewin Dolphin.

We've had some fantastic events throughout the year which has kept fundraising efforts high whilst also refreshing our brand to keep CF Warriors moving forward with the times.

The charity is now nearing the end of its fully funded PhD studentship at the University of Portsmouth. Our PhD student Lauren Clayton has submitted her research which is extremely exciting for us and the CF community.

REPORT OF THE TRUSTEES

Report Of The Trustees For The Period 1st April 2023
To 31st March 2024

The Trustees present their report and financial statements for the period ended 31st March 2024.

Structure, Governance & Management

CF Warriors is a Charitable Incorporated Organisation, governed by its constitution as set out in the charity's governing document.

Board of Trustees

Joshua Llewellyn-Jones OBE - Chair
Paul Langmaid CBE
Steve Doyle
James Gadd

CF Warriors continues to recruit skilled and experienced trustees to the board to strengthen our team and drive our vision forward.

Management

Joshua Llewellyn-Jones OBE
Joshua manages the day-to-day operations of the charity, ensuring that the CF Warriors charity delivers its vision and mission each week to the families that register with us. This includes all correspondence to the charity, managing the Warrior Pack Program, event organisation and fundraising, website and social media channels, and liaising with our Research Funding Partners at the University of Portsmouth.



**WHAT WE'VE
DELIVERED THIS
YEAR**

WARRIOR PACK PROGRAM

This year we have sent out 70 Warrior Packs to families around the world.

Whilst the packs cost around £50 to produce, postage varies between £3 to £30 depending on which country the recipient lives. We also receive requests from returning families for larger clothing as their children outgrow their Warrior Packs. It's our commitment to these children to see these needs wherever possible as part of our core charitable objectives.

We receive so many kind messages from families along with pictures of their children in the CF Warriors clothing. These families often become heavily involved in the charity by fundraising for us, hosting their own events or even volunteering at our events. We will always be grateful for all the hard work and time individuals give so readily to the charity to support our cause.



RESEARCH FUNDING

Background:

New medicines like Kaftrio can help people with cystic fibrosis (CF) feel better and healthier. However, there are worries about rising obesity and heart disease risks, and we don't know if these medicines can really make fitness better. We also need to learn more about how they affect hydration, salt intake, and heat-related illnesses. This research aimed to find out how Kaftrio affects these areas to give better advice on exercise and nutrition for people with CF.

Objectives: This PhD aimed to study how Kaftrio affects exercise, muscle function, body composition, and heart and blood vessel health. We also looked into how people feel about hydration, salt intake, and how their bodies manage heat. The goal was to gather important information to help improve exercise and nutrition for people with CF.

Methods: We did two main studies: the Understand-CF study, which looked at fitness and health, and another study focused on hydration and heat stress. We invited people with CF on Kaftrio and compared them to healthy people of the same age and sex. We measured aerobic fitness through exercise tests while checking their breathing, heart, and blood vessel responses. We tested leg muscle function using different physical tests and special tools. We also checked body composition, heart and blood vessel health, and physical activity. A survey and lab study looked at hydration, salt intake, and how the body deals with heat.

Key Findings: This research gave new information about exercise and muscle function in people with CF on Kaftrio. It showed that they can have normal muscle strength and body composition, but their fitness may still be lower, possibly because of heart problems. While small blood vessels worked well, there might be issues with larger ones. We are still looking at data about hydration and heat issues. This shows that exercise and healthy eating are more important than ever for people with CF, and we need to create better hydration plans for exercise.

RESEARCH FUNDING

Impact and Conclusions: This research shows that while Kaftrio helps, it isn't a complete solution; exercise and nutrition are very important for overall health. We need to create personalised plans to manage heart health, and more research is needed to improve hydration and exercise preparation for people with CF, especially as the climate changes.

Future Plans: We plan to keep this research going, using what we learned to support larger projects and working closely with CF Warriors. Future studies will check these results in people with CF with more advanced disease and look at long-term heart and muscle health. We will also explore ways to improve exercise and nutrition, making specific guidelines for hydration and preparing for exercise in hot weather.

The full report on our Research Findings is also available for download at <https://cfwarriorsorg.com/shop/f7b289c6-94e4-454e-98a7-15d7719a4941>

EVENTS

24hr Warrior Games 2023

Enzo Gibson's CF Warriors Triathlon

Jason Blight's Boxing Fundraiser

Alex Rainey's Swimming Fundraiser

Nikki Barnsley-Walker's Fundraiser

Michael Lewis's tandem Skydive

Charlie Cheese's 65 mile row for CF Warriors

Ollie Payne's Skydive for CF Warriors

Freddie Davy's Skydive for CF Warriors

Jordan Anaya's Skydive for CF Warriors

Polly Cooper's Skydive for CF Warriors

PLANS FOR THE FUTURE

To spread the awareness of the research findings and educate Cystic Fibrosis families on the importance of exercise and good nutrition. Whilst new medications are really powerful for some people with Cystic Fibrosis, they don't negate the need for consistent exercise and keeping on top of a healthy, balanced diet.

To continue to grow the Warrior pack program. We want to try and reach as many children as possible and where possible, support them as they outgrow their Warrior Packs.

THANK YOU

Thank you's for supporting & volunteering

Adrian Llewellyn-Jones

Angharad Jenkins

Dawn Llewellyn-Jones

Paul Madley

Paul Langmaid CBE

Stephen & Karen Doyle

James Gadd

Buffoon Film & Media

Paul Fears Photography

Enzo & the Gibson family

Caroline Sims

Johnny Gray

Kyle Young

All the staff at 29 Regiment

David Doidge

Lucy Jones

Acapela Studios

Jayne James

BRIEF STATEMENT OF POLICY ON RESERVES

During the year, our expenditure exceeded income by £13,210 and therefore our cash reserves at 31 March 2024 reduced to £19,885 (FY 23: £33,035) in unrestricted funds.

However, gross donations and event income during the year actually increased from £51,838 to £77,379. We did not receive any grant income during the year, compared to the £25,000 we received in the previous year. The increase in donation and event income is testament to the hard work of our team and the engagement they engender in the CF community and beyond.

During the year, PhD funding was some £13,800 more than last year and this is the principle reason for the deficit recorded in the year compared to the surplus reported in the previous year.

We are confident that with the events and plans we have in place for the coming year 2024-2025, our financial position will return to surplus and we will be able to meet all our financial obligations regarding the Warrior Pack Program in the years ahead and expanding our reach across the CF community.



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name

CF Warriors

No (if any)

1178063

Receipts and payments accounts

CC16a

For the period
from

Period start date
4/1/23


To

Period end date
3/31/24

Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Donations	70,481	-	-	70,481	41,846
Event sponsorship and ticket sales	6,898	-	-	6,898	9,994
Grants	-	-	-	-	22,500
Loans received to fund capital purchases	2,600	-	-	2,600	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total(Gross income for AR)	79,979	-	-	79,979	74,340
A2 Asset and investment sales, (see table).					
	- 0	- 0	- 0	-	
	- 0	- 0	- 0	-	- 0
Sub total	- 0	- 0	- 0	-	- 0
Total receipts	79,979	- 0	- 0	79,979	74,340
A3 Payments					
Grants to fund research	27,000	-	-	27,000	13,200
"CF Warrior" packs distributed free of charge	8,977	-	-	8,977	9,028
Employee costs	24,816	-	-	24,816	23,307
Office costs and fundraising expenses	11,961	-	-	11,961	7,832
Social media expenses	599	-	-	599	857
Legal and professional fees	1,296	-	-	1,296	1,391
Communication and IT expenses	2,567	-	-	2,567	2,905
Event expenses	12,618	-	-	12,618	8,068
Bank and payment processing fees	- 0	-	-	-	19
Insurance	600	-	-	600	759
Interest	155	-	-	155	22
Purchase of capital assets	2,600	-	-	2,600	-
	-	-	-	-	-
Sub total	93,189	-	-	93,189	67,408
A4 Asset and investment purchases, (see table)					
	- 0	- 0	- 0	-	
	- 0	- 0	- 0	-	- 0
Sub total	- 0	- 0	- 0	-	- 0
Total payments	93,189	- 0	- 0	93,189	67,408
Net of receipts/(payments)	- 13,210	-	-	- 13,210	6,932
A5 Transfers between funds	- 0	-	-	-	-
A6 Cash funds last year end	33,095	-	-	33,095	26,163
Cash funds this year end	19,885	-	-	19,885	33,095

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	Cash at bank	19,885	-	-
			-	-
		-	-	-
	Total cash funds	19,885	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
	Details	Unrestricted funds	Restricted funds	Endowment funds
		to nearest £	to nearest £	to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
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 liability relates	Amount due (optional)	When due (optional)
B5 Liabilities	Other taxation and social security	Unrestricted	2,676	
	Loan	Unrestricted	2,600	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees		Joshua Llewellyn-Jones		30/01/2025



Section A

Independent Examiner's Report

**Report to the trustees/
members of**

CF Warriors

**On accounts for the year
ended**

31 March 2024

**Charity no
(if any)**

1178063

Set out on pages

The Trustee's Report and Accounts set out on pages 1 to 14 of the attached report,

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31 March 2024.

**Responsibilities and
basis of report**

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.

Signed:

Date: 30 January 2025

Name:

Stephen Thomas

**Relevant professional
qualification(s) or body
(if any):**

ACA

Address: 4 Gold Tops, Newport, NP20 4PG

CF WARRIORS

England & Wales - Charity number 1178063

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2022/23

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INTRODUCTION

CF Warriors was founded to motivate, inspire and support children with cystic fibrosis on their journey to a longer, happier and healthier life. Our mission is to raise awareness of the benefits of sport and exercise to the CF community across the globe, through events, our Warrior Pack Program, and the publication of vital research funded by the charity.

It's been an exciting year for the charity with events making a full come-back. Whilst there's still been some challenges due to Covid-19, supporters, volunteers and CF families have been very keen to attend events, fundraise and raise awareness for children with Cystic Fibrosis.

The charity is now in its second year of its fully funded PhD studentship at the University of Portsmouth. Our PhD student Lauren Clayton is well underway with her research and the research program has been refined and features some world first observational study to understand the fitness, body composition, physical activity and sleep patterns in people with cystic fibrosis on cystic fibrosis transmembrane conductance regulator modulator therapy compared to healthy controls, providing World first data in a number of areas.

Our Warrior Pack Program has continued to be incredibly popular over the last 12 months and we have added even more contents to the packs, whilst still managing to keep the costs to around £50 per pack.

REPORT OF THE TRUSTEES

Report Of The Trustees For The Period 1st April 2022 To 31st March 2023

The Trustees present their report and financial statements for the period ended 31st March 2022.

Structure, Governance & Management

CF Warriors is a Charitable Incorporated Organisation, governed by its constitution as set out in the charity's governing document.

Board of Trustees

Joshua Llewellyn-Jones OBE - Chair

Paul Langmaid CBE

Steve Doyle

Paul Floyd

CF Warriors continues to recruit skilled and experienced trustees to the board to strengthen our team and drive our vision forward.

Management

Mark Llewellyn-Jones - CEO

As CEO, Mark manages the day-to-day operations of the charity, ensuring that the CF Warriors charity delivers its vision and mission each week to the families that register with us. This includes all correspondence to the charity, managing the Warrior Pack Program, event organisation and fundraising, website and social media channels, and liaising with our Research Funding Partners at the University of Portsmouth.



WHAT WE'VE DELIVERED THIS YEAR

WARRIOR PACK PROGRAM

This year we have sent out 120 Warrior Packs to families around the world, and despite rising prices, we have managed to keep the costs of our packs to £50 per pack (not including postage), whilst adding even more items to them to help children stay active and motivate and inspire them to be the best versions of themselves.

Whilst the packs cost around £50 to produce, postage varies between £3 to £30 depending on which country the recipient lives. We also receive requests from returning families for larger clothing as their children outgrow their Warrior Packs. It's our commitment to these children to see these needs wherever possible as part of our core charitable objectives.

We receive so many kind messages from families along with pictures of their children in the CF Warriors clothing. These families often become heavily involved in the charity by fundraising for us, hosting their own events or even volunteering at our events. We will always be grateful for all the hard work and time individuals give so readily to the charity to support our cause.



RESEARCH FUNDING

Summary of Progress Made by PhD Student Lauren Clayton.
April 2022 – March 2023

Lauren the PhD student has successfully completed 1.5 years of study and training. Her PhD title has now been refined from: Exercise and Nutrition for People with Cystic Fibrosis in the Modulator Era to Central, peripheral and thermoregulatory physiological response to exercise in ambient and heat stress conditions in people with cystic fibrosis on modulator therapy

Programme of research:

1 – Evaluate the current hydration / salt requirements for people with CF (global) – underway – Saynor leading review on this topic – 50% complete

2 – Study 3: Lived experiences of salt supplementation, hydration, thermoregulation, sweat and heat-related illness during rest, exercise and exposure to hot environments in people with cystic fibrosis: an international cross-sectional survey-based study. Survey responses are slow, ethics being amended and in conversations with other international CF organisations to assist with sharing this use

3 – Laboratory Study: The Sweat-CF study: A study to assess the sweat response, sweat composition and thermoregulatory response to exercise in heat in people with cystic fibrosis on cystic fibrosis transmembrane conductance regulator modulator therapy compared healthy controls.

This is a World first study – only a handful of studies have explored the responses of people with CF in the heat – none using the techniques we are using and none on CFTR modulator therapy. Will provide valuable insight into the baseline presentation of people with CF but also then how their body's respond.

4 – Laboratory Study: The Understand-CF Study: An observational study to understand the fitness, body composition, physical activity and sleep patterns in people with cystic fibrosis on cystic fibrosis transmembrane conductance regulator modulator therapy compared to healthy controls.

RESEARCH FUNDING

Providing World first data in a number of areas.

1. It is unlikely that modulators alone can improve and then maintain fitness at high, healthy levels (case studies suggesting this) – this will provide gold standard data regarding the current picture in CF in the modulator era – detailed physiological assessments will help us understand a number of key organ systems and to what extent they can be ‘fixed’ with modulators
2. Body composition (fat, muscle and bone) being assessed using gold standard best measures of DEXA as well as detailed assessment of muscle function
3. Cardiovascular health is a big concern in CF at present and in the context of ageing – within which diet and exercise are going to be essential. We have collected the most comprehensive set of data in People with CF representing cardiovascular health and the ETI era provides novel insight into what the future may look like

All of the above are hot topics in cystic fibrosis at present and moving forward, placing CF Warriors firmly on the map from a funder perspective.

The heat-related work was also recently launched to parliament at the parliamentary launch of ‘Red Alert: Developing a Human-centred National Heat Resilience Strategy’, a collaboration between the Physiological Society and Faculty of Public Health. Saynor (co-Lead of the Clinical Hub at The Physiological Society) was an invited expert and highlighted in particular the need for specific attention to be paid to support vulnerable populations, showcasing people with cystic fibrosis as a key example of this.

RESEARCH FUNDING

6 months – 1 year (April 2022 – September 2022)

✓ The Understand-CF study ethics application submitted, ethics meeting attended, approval grant by the South Central – Berkshire B NHS Research Ethics Committee and the Health Research Authority (22/SC/0168) and study pre-registered on clinicaltrials.gov (NCT05857709).

The ethical application process:

Applying for NHS ethics approval involves 5 key steps:

First is the development/preparation of your research proposal and study design alongside all participant facing documents, including participant information sheets, informed consent forms, posters, questionnaires/scales and any other material needed for the study to run.

Next is the application form that must be submitted through the Integrated Research Application System (IRAS). This application must be completed in line with your research proposal and study design. You must provide a descriptive explanation of the study including, objectives, methods to be used, what is involved for participants, risks/risk prevention and any benefits.

Following submission of your research proposal and application, it will go to a Research Ethics Committee consisting of professionals, experts and lay members for review, who will consider all ethical aspects to ensure safety to all participants.

You will often attend a Committee meeting; this gives the committee time to ask any further questions about the proposal and design and raise any concerns they may have.

After the Research Ethics Committee have reviewed the application, you will be given feedback and revisions. You must address any concerns and adjust your protocol and/or participant facing documents where necessary and resubmit your application for a second review.

Once the second review has happened, provided you have addressed any concerns and made the adjustments the Research Ethics Committee will grant you favourable ethical approval and you can begin recruitment.

RESEARCH FUNDING

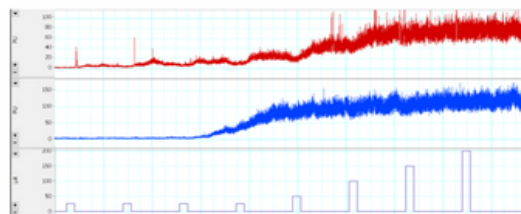
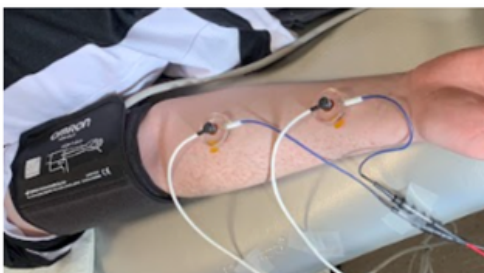
✓ **The Understand-CF study** up-skilling in protocol methods.

Before data collection could commence Lauren dedicated considerable time to learning and becoming proficient in a wide range of advanced laboratory techniques and the analysis. Techniques include; Insulin and Acetylcholine Iontophoresis and Flow-mediated dilation technique for assessment of blood vessel health; Cardiopulmonary Exercise Testing for the measure of aerobic fitness, alongside the use of a Near-infrared Spectroscopy device and a Physioflow device for measures of muscle de-oxygenation and haemodynamic responses, respectively; globally recommended field-based exercise tests for measure of muscle function; use of the Isokinetic dynamometer for measures of muscle function; dual-energy X-ray absorptiometry (DEXA) scanner for the means of measuring body composition; and use of a wrist -worn accelerometry device for the measure of physical activity and sleep behaviours.

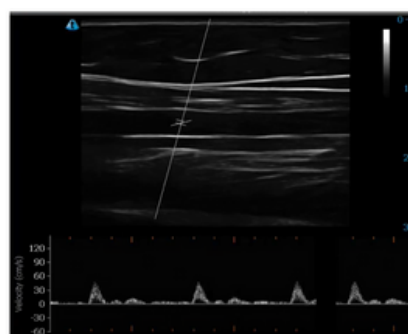
To become proficient in DEXA scanning, Lauren completed the Ionising Radiation (Medical Exposure) Regulation Training. The training consisted of two components; a taught element, covering the basics and regulations; and an in-person training day which covered the use of equipment, correct positioning and the analysis of the scans.

Insulin and Acetylcholine Iontophoresis:

Flow mediated dilation technique



Flow mediated dilation technique

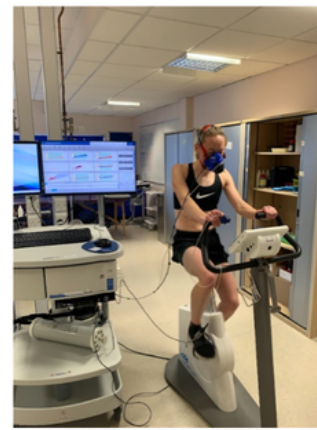


RESEARCH FUNDING

✓ **The Sweat-CF study Pilot testing.** Pilot testing was a crucial phase that was completed in 7 participants to assess and refine our protocol, techniques and overall approach in the development of the project. By pilot testing, we were able to practice the methods and techniques as well as uncover any potential issues or challenges that arise during the study.



During this time, we were able to adjust the length and intensity of the protocol to ensure it was comprehensive yet manageable for our population and identify the most suitable temperature conditions for conducting our research.



✓ Placement with Dr Don Urquhart in Edinburgh. Lauren successfully secured £500 to undertake a placement at the Royal Hospital for Sick Children, Edinburgh, UK. During Lauren's time there, she had the opportunity to shadow Dr Don Urquhart as well as key members of his team. Dr Don Urquhart is a well-respected clinical academic in Paediatric Respiratory Medicine working at the Royal Hospital for Children and Young People and an Honorary Reader at the University of Edinburgh. Dr Urquhart co-chairs the [European Cystic Fibrosis \(CF\) Society \(ECFS\)](#).

RESEARCH FUNDING

Exercise working group and has a long-standing collaborative relationship with, Dr Zoe Saynor.

The activities on this placement included; (1) observing clinical respiratory testing, including cardiopulmonary exercise testing (CPET) in children with a number of pathologies; (2) meeting researchers actively engaged in CF research projects involving exercise. Observing how research is conducted in a clinical exercise physiology lab; (3) giving a talk about the research funded by CF Warriors to the team in Edinburgh, sharing the work and promoting the charity to researchers and medical professionals actively working in the field of cystic fibrosis.

✓ **Independent medical officer training day.** During the independent medical officer training day, Lauren engaged in a series of comprehensive workshops learning and gaining competencies in a number of critical medical skills enhancing Lauren proficiency in handling diverse medical scenarios. These workshops encompass:

- **ECG workshop:** This session was delivered to learn the intricacies of Electrocardiogram (ECG) application and interpretation. The session provided a detailed exploration of the cardiac system, gaining an understanding of the components of the ECG waveforms. Practical hands-on training focused on the electrode placement, recognising normal versus abnormal readings and troubleshooting. This is an essential skill for Lauren since all participants over 30 must have an ECG before they can take part in both the Understand-CF and the Swear-CF study.
- **Resuscitation workshop:** This session was designed to stimulate real-life emergency situations and provided Lauren with essential skills needed during resuscitation scenarios. During this session Lauren learnt and practiced life support techniques, including cardiopulmonary resuscitation (CPR), airway management and defibrillation.
- **Extreme environments laboratory simulations workshop:** This session was designed to replicate realistic scenarios that may occur in the University of Portsmouth's extreme environments laboratory to prepare researchers for the unique challenges of working within extreme environments such as the heat, water or high altitude. It prepares researchers from understanding and responding to heat-related illnesses, hypothermia, seizures, diabetic emergencies and other environmental emergencies.

RESEARCH FUNDING

✓ **First aid at work training day.** The University of Portsmouth's first aid at work training day provides a chance to refresh skills and stay updated on guidelines and techniques. During this training there is an overview of the importance of first aid and its role in emergency situations. It covers basic life support and CPR, managing bleeding and wounds and airway management.

✓ **Attendee at the University of Portsmouth Rehabilitation conference.**

✓ **Major review:** As a full-time postgraduate researcher Lauren was required to undergo a Major review following 1 year of her PhD. The purpose of a Major Review is to confirm the student's capability to satisfactorily complete a PhD thesis. To complete this Lauren was required to write up and submit a Major Review document stating the aims of her research, a literature review, an outline of her research, a provisional timetable for the programme of research, her research progress and an outline of any researcher development activities she has completed. In addition, Lauren had to prepare and present a presentation to the school. Lauren successfully completed her Major Review - COMPLETE

RESEARCH FUNDING

1 year – 1.5 years (October 2022 – March 2023)

✓ The Understand-CF study recruitment and data collection ongoing:

Recruitment: Lauren has been working closely with CF clinicians and physiotherapists within the adult and paediatric CF teams at the University Hospital Southampton to identify individuals that meet the criteria for participation in the studies. Time has been dedicated to engaging with potential participants to provide details about the research and generate interest. Once potential participant express interest further screening is completed where necessary and participants are enrolled into the study.

Data collection: Lauren began data collection in January 2023. Data collection involves bring participants in to the Laboratories at the University of Portsmouth and implementing the ethically approved and predetermined protocol and advanced laboratory techniques. Before each testing session, all equipment must be set-up and calibrated to ensure accurate measurements are taken. After each testing session, certain techniques require additional analysis before the final results could be recorded.

✓ The Sweat-CF study ethics application submitted, ethics meeting attended, approval granted by South East Scotland NHS Research Ethics Committee 01 and the Health Research Authority (22/SS/0102) and study pre-registered on clinicaltrials.gov (NCT05896488).

RESEARCH FUNDING

✓ **The Sweat-CF study** up-skilling in protocol methods. Prior to commencing the study, Lauren spent considerable time in gaining expertise in the operation of the environmental heat chamber alongside various specialised equipment used to assess individuals' physiological responses and tolerance to heat exposure. Specially Lauren has learnt how to use:

Physiological monitoring equipment:

- Rectal thermistors: these are probes used to measure core body temperature
- Skin thermistors: these are instruments stuck to the skin to assess changes in skin temperature
- Heart rate monitor: a device used to monitor heart rate changes during a heat stress test
- Osmometer: a device used to assess hydration status before and after a heat stress test
- Q sweat: an instrument placed on an individual's skin to measure local sweat rate, used in assessing an individual's ability to regulate body temperature through sweating.
- SweatChek: a device used to measure the composition of sweat following a heat stress test
- Laser doppler probe: an instrument placed on an individual's skin to measure vascular response, used in assessing an individual's ability to regulate body temperature through convection
- Iodine patch: This is a piece of cotton paper that has been soaked in iodine. This is pressed on the skin and used to assess how many sweat glands are active
- Metabolic cart: this is a device used to measure various respiratory parameters

RESEARCH FUNDING

✓ **Study 3 survey design:** this involved defining the research objectives and hypotheses, determining the survey methodology and developing the survey questions. As such the study has been designed to collect cross-sectional data on the experience of people with CF in the heat, during exercise and their current understanding of salt supplementation and hydration guidelines. It will be disseminated online using the onlinesurveys.ac.uk interface (JISC, Bristol, UK) with survey links distributed via social media to people with CF ≥ 16 years old worldwide and parents/guardians of people with CF aged 6 - 15 years to represent the paediatric experiences. The survey has been designed into 4 sections.

Briefly, the survey will capture 1: participants' demographic information; 2: information regarding physical activity and exercise behaviours; 3: experiences sweating and the composition of this, alongside other symptoms of exertional heat-illness and dehydration and 4: knowledge and use of salt and hydration guidelines, current dietary salt intake and use of salt and electrolyte supplements during rest, exercise and when in a hot environment. The survey is composed predominantly of multiple-choice answers. Where appropriate, participants will be asked whether they would like to add any additional comments to the statement.

✓ **Study 3 completion of ethical application** to be submitted for review to the Science and Health Faculty Ethics Committee. The ethical application comprises of 14 main sections, including details on; the study title and key dates; applicant details; details of peer review; funding details; insurance/indemnity arrangements; aims and objectives/hypotheses; justification/summary of study; description of methods/protocol and risks; compliance with laws, codes, guidance, policies and procedures; recruitment of participants; data management; publication/impact/dissemination plans and references.

✓ **Independent medical officer training day:**

- ECG workshop
- Resuscitation workshop
- Extreme environments laboratory simulations workshop

COMPLETE

RESEARCH FUNDING

Next steps:

1.5 years – 2.5 years (April 2023 – March 2024)

Over the upcoming year, our primary focus will be to continue recruitment and data collection for the Understand-CF and Sweat-CF study. Alongside this we will initiate the write up of our research findings, whilst attending international conferences to disseminate our research finding.

✘ The Understand-CF study and the Sweat-CF study recruitment and data collection continued: Lauren will continue to work closely with CF clinicians and physiotherapists within the adult and paediatric CF teams at the University Hospital Southampton to identify individuals that meet the criteria for participation in the studies. Time will continually be dedicated to engaging with potential participants to provide details about the research and generate interest. Once potential participant express interest further screening will be completed where necessary, and participants will continue to be enrolled into the study.

✘ The Understand-CF study research paper writing: data collected during the Understand-CF study will be written up into 3 research papers, of which titles have been refined to:

- 1: Mechanisms underpinning fitness during ramp exercise in people with cystic fibrosis on Elexacaftor-Tezacaftor-Ivacaftor.
- 2: Cardiovascular health and physical activity in people with cystic fibrosis on Elexacaftor-Tezacaftor-Ivacaftor: a cross-sectional, observational, single-centre cohort study.
- 3: Peripheral muscle function and body composition in people with cystic fibrosis on Elexacaftor-Tezacaftor-Ivacaftor: a cross-sectional, observational, single-centre cohort study.

RESEARCH FUNDING

✘ Study 3 ethics application to be submitted and approval granted by the Science and Health Faculty Ethics Committee and data collection to begin.

✘ Lauren will apply for funding to attend the European College of Sport Science Conference 2023 in Paris. Attending a conference will provide Lauren with numerous opportunities to learn and develop as a researcher. It will provide a chance to access presentations and keynote speeches by experts sharing the latest findings and advancements as well as providing an opportunity to connect with peers and meet experts in the same field.

✘ Lauren will apply for funding to attend the Near-infrared spectroscopy workshop 2023 in London.

✘ Lauren plans to submit a poster to the Research and Innovation Showcase at the University of Portsmouth. This will serve as a platform to highlight the being funded by CF Warriors.

✘ Annual Review: As a full-time postgraduate researcher Lauren is required to undergo an Annual review following 2 years of her PhD. The purpose of an Annual Review is to confirm the student's capability to satisfactorily complete a PhD thesis. To complete this Lauren will be required submit and present a presentation to her assessors outlining the background of her research, her thesis outline, an overview of each study, a summary of progress, a plan for the year ahead and all research and personal development undertaken.

✘ Lauren is planning to obtain funding through the postgraduate research students conference bursary. Her aim is to submit multiple abstracts for presentation at the European Cystic Fibrosis Society Conference 2024 in Glasgow. If successful Lauren will present the research findings to an audience comprising of CF researchers, clinicians and healthcare professionals as well as patient advocates and supports groups dedicated to individuals affected by cystic fibrosis.

IN PROGRESS / FUTURE PROGRESS

EVENTS

Iain Maynard Charity Ball - 2/4/22

Warrior Games - June 2022 - Cancelled to September 22

CFW Lunch September 2022 -

Jayne James Fashion Show - Loulou Boutique

Jolly Jingle Jog for CF Warriors - 4/12/22

Xmas at Acapela - 12/12/22

6500 Walk for Violet - Team Ditcham

Warrior Games 2022

Kerrie's Black & White Ball and Sports Activities Event

50 mile bike ride challenge! (Scarborough-Whitby-Scarborough)

24hr Warrior Games 2022

Linda's Charity BBQ and Rob Lamberti

FTR Ladies Do Warrior Games 2022

Warrior Games 2022

Rosies page

Janes page

Lara's page

Remembering Matthew

Lara's page

In memory of Matthew - Lara Massie

Becs Swansea 70.3 Ironman for CF Warriors

Max & Pattie Dobbyne- Childrens Christmas Jingle Jog

Woody's Warriors' Page Warrior Games 2023

Kerrie Stoner who rallied the troops in Dover for the Warrior Games and helped to make a huge difference - Whiteciffs Warriors

Anna's page - Anna Gould

Elie and Anna Run London

Pain Score 10! - Warrior Games 2023

ASC WARRIORS take on the warriors games 2023

Warrior Games 2023

Tom, Joe, James and Callum's fundraiser for CF Warriors.

PLANS FOR THE FUTURE

To complete our Research Funding Program, and disseminate all the relevant findings from the 3-year project to the wider CF community. Once all the information is gathered, we can then look to send this information out to the CF community through marketing campaigns.

To continue to grow the Warrior pack program. We want to try and reach as many children as possible and where possible, support them as they outgrow their Warrior Packs.

THANK YOU

Thank you's for supporting & volunteering

Emma Floyd

Dawn Llewellyn-Jones

Adrian Llewellyn-Jones

David Doidge

Anna Gould

Enzo & the Gibson family

Caroline Sims

Johnny Gray

Kyle Young

All the staff at 29 Regiment

Donations

Lumen Financial - £2500 Sharon Holmes , Jason Gavin Holmes

Denval Co Ltd - Jemma & Tricia Morris

Denver Drilling

Nigel John & Hern & Crabtree (£800)

Ben Shephard (Book) - £500

Inverhow - £250

Moondance Foundation - £12,500

Waterloo Foundation - £800 - Auction Winner

Waterloo Foundation - £10,000

Dani Warburton - £1267 - Violet Ditcham 6500 Event

Amanda Arter

Jayne James & Loulou Boutique

Chris Stroud - auction donations - £2624.35

Denise Yapp

ST Tewdrics House - 350

Acapela - £1592 - Tickets

Scott Wheeler - £615 & £827.50 - HMP Hewell to Calais

Rowing Event

Karen Doyle

Sam Williams - £100

St Tewdrics House - £350 - Lunch Sponsorship - October 2022

Jenny Wildig - £500 Virtual Warrior Games

Dr Issie Graham

Rosie Moriarty-Simmonds OBE

BRIEF STATEMENT OF POLICY ON RESERVES

Cash reserves at 31 March 2022 were £33,095 in unrestricted funds. To continue our Warrior Pack Program alongside this research funding, it is necessary to hold at least £25,000 to cover the running costs of the charity.

We are confident that with the number of plans we have in place for the coming year 2023-2024, our financial position will improve considerably, and we will be able to meet all our financial obligations regarding our Research Funding and the Warrior Pack Program in the years ahead.



Section A

Independent Examiner's Report

Report to the trustees/
members of

CF Warriors

On accounts for the year
ended

31 March 2023

Charity no
(if any)

1178063

Set out on pages

The Trustee's Report and Accounts set out on pages 1 to 8 of the attached report,

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31 March 2023.

Responsibilities and
basis of report

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.

Signed:

Date:

31 January 2024

Name:

Stephen Thomas

Relevant professional
qualification(s) or body
(if any):

ACA

Address:

4 Gold Tops, Newport, NP20 4PG



Receipts and payments accounts

For the period from	Period start date	To	Period end date
	4/1/22		3/31/23

Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds
	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts				
Donations	41,846	-	-	41,846
Event sponsorship and ticket sales	9,994	-	-	9,994
Grants	22,500	-	-	22,500
	- 0	-	-	-
	- 0	-	-	-
	- 0	-	-	-
	- 0	-	-	-
Sub total (Gross income for AR)	74,340	-	-	74,340
A2 Asset and investment sales, (see table).				
	- 0	- 0	- 0	-
	- 0	- 0	- 0	-
Sub total	- 0	- 0	- 0	-
Total receipts	74,340	- 0	- 0	74,340
A3 Payments				
Grants to fund research	13,200	-	-	13,200
"CF Warrior" packs distributed free of charge	9,028	-	-	9,028
Employee costs	23,307	-	-	23,307
Office costs and fundraising expenses	7,832	-	-	7,832
Social media expenses	857	-	-	857
Legal and professional fees	1,391	-	-	1,391
Communication and IT expenses	2,905	-	-	2,905
Event expenses	8,088	-	-	8,088
Bank and payment processing fees	19	-	-	19
Insurance	759	-	-	759
Interest	22	-	-	22
	-	-	-	-
	-	-	-	-
Sub total	67,408	-	-	67,408
A4 Asset and investment purchases, (see table)				
	- 0	- 0	- 0	-
	- 0	- 0	- 0	-
Sub total	- 0	- 0	- 0	-
Total payments	67,408	- 0	- 0	67,408
Net of receipts/(payments)	6,932	-	-	6,932
A5 Transfers between funds	- 0	-	-	-
A6 Cash funds last year end	26,163	-	-	26,163
Cash funds this year end	33,095	-	-	33,095

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds	Restricted funds
		to nearest £	to nearest £
B1 Cash funds	Cash at bank	33,737	-
	Loan balance	- 642	-
		-	-
	Total cash funds	33,095	-
	(agree balances with receipts and payments account(s))	OK	OK
		Unrestricted funds	Restricted funds
		to nearest £	to nearest £
B2 Other monetary assets		-	-
		-	-
		-	-
		-	-
		-	-
		-	-
		Fund to which asset belongs	Cost (optional)
B3 Investment assets			-
			-
			-
			-
			-
		Fund to which asset belongs	Cost (optional)
B4 Assets retained for the charity's own use			-
			-
			-
			-
			-
			-
			-
			-
		Fund to which liability relates	Amount due (optional)
B5 Liabilities	Other taxation and social security	Unrestricted	-
			-
			-
			-
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	

CC16a

Last year

to the nearest £

42,306

-

-

-

-

-

42,306

- 0

- 0

42,306

-

13,731

23,308

7,286

2,800

1,176

2,086

861

413

341

-

-

52,001

- 0

52,001

- 9,695

-

35,858

26,163

CF WARRIORS

England & Wales - Charity number 1178063

Accounts



WARRIORS
SUPPORTING CHILDREN WITH CYSTIC FIBROSIS

ANNUAL REPORT
2021-2022



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Introduction

CF Warriors was founded to motivate, inspire and support children with cystic fibrosis on their journey to a longer, happier and healthier life. Our mission is to raise awareness of the benefits of sport and exercise to the CF community across the globe, through events, our Warrior Pack Program, and the publication of vital research funded by the charity.

It has been another challenging year for CF Warriors, with the impact of Covid-19 still being felt in Wales and across the globe, particularly affecting our community of families who have been dealing with a great deal of isolation and worry throughout these uncertain times. But there are a great many things to be hopeful for as restrictions have eased and life has begun to return to some form of normality. The charity has had to adapt once again to these challenges, to enable us to continue to provide our services to families living with cystic fibrosis in the UK and abroad.

Restrictions in Wales have meant that nearly all the events we had hoped to host in the UK were abandoned, however it is with a great deal of gratitude that we can say our community of supporters found unique ways of helping us by organising so many of their own events to fundraise for the charity.

The charity has begun its fully funded PhD studentship at the University of Portsmouth, and our PhD student Lauren Clayton has begun work on several studies, exploring the effects of not only exercise, but also nutrition, for people with cystic fibrosis in the modulator era. This is a huge step forward for the charity, one which we are so proud to be a part of, and we are incredibly excited to be helping the next generation of researchers explore the possibilities that the new modulator drugs available in the community are bringing

Our Warrior Pack Program is also going strong and bringing some much needed joy to families around the world. Our aim as always with this program is to include every child and ensure every request for a Warrior Pack, no matter where they are in the world, is met with a positive response, and no child is left behind.



Mark Llewellyn-Jones

CEO

Report Of The Trustees For The Period 1st April 2021 To 31st March 2022

The Trustees present their report and financial statements for the period ended 31st March 2022.

Structure, Governance & Management

CF Warriors is a Charitable Incorporated Organisation, governed by its constitution as set out in the charity's governing document.

Board of Trustees

- Josh Llewellyn-Jones OBE - Chair
- Paul Langmaid CBE
- Steve Doyle
- Paul Floyd
- Jane Sharpe (Resigned 1/3/2022)

CF Warriors continues to recruit skilled and experienced trustees to the board to strengthen our team and drive our vision forward.

Management

- Mark Llewellyn-Jones - CEO

As CEO, Mark manages the day-to-day operations of the charity, ensuring that the CF Warriors charity delivers its vision and mission each week to the families that register with us. This includes all correspondence to the charity, managing the Warrior Pack Program, event organisation and fundraising, website and social media channels, and liaising with our Research Funding Partners at the University of Portsmouth.

What We Have Delivered This Year

CF Warriors has two main objectives that help deliver the vision of the charity.

Warrior Pack Program

Firstly, there is our Warrior Pack Program which is ongoing and is designed to inspire and motivate families to and show children suffering with cystic fibrosis that they are part of a larger community. This year we delivered 253 Warrior Packs to families around the world dealing with cystic fibrosis.

Research Funding

We have begun our very first Research Funding Program, which is 6 months into a 3-year project in partnership with the University of Portsmouth. The charity's aims through the research funding are to provide information to parents regarding nutrition, hydration and salt intake when their children are exercising or doing physical activities. The research is being undertaken by Lauren Clayton at the School of Sport, Health and Exercise Science at the University of Portsmouth. By funding this program, we are hoping to inspire the next generation of researchers to concentrate their efforts on cystic fibrosis, and by doing so, help families dealing with this disease to become more well informed in the nutritional problems facing children growing up with cystic fibrosis in the modulator era, and break down some of the barriers that often cause children to stop using exercise as a means to staying fit and healthy.

Warrior Pack Program

We were able to continue this program throughout the pandemic despite lockdowns and government restrictions, and our Warrior Packs have been a huge success again this year, with us sending out over 250 packs to children from around the world, a very similar total to the previous year. We have also found that it has been a great way for us to connect with the CF Warriors community, to support children living with cystic fibrosis in what are incredibly lonely circumstances, particularly with the various restrictions that we have all had to endure over the last 12 months, and the uncertainty this has brought to the community.

The packs cost around £50 to produce, and the costs of sending them vary depending on which country the recipients live in, these costs range from £3 to £30. We also receive requests from many returning families for larger clothing as their children outgrow their Warrior Packs. It is our commitment to these children to meet these needs wherever possible as part of our core charitable objectives.

We receive so many kind messages from families expressing their gratitude and many have become heavily involved in the charity, helping us either by fundraising at their own events, or giving up their valuable time volunteering for the charity at one of ours. We will always be grateful for all the hard work and time individuals give so readily to the charity to support our cause.

Heatmap showing the global distribution of our Warrior Pack Program



Research Funding

Partnership between the School of Sport, Health and Exercise Science (University of Portsmouth) and CF Warriors

This partnership is an initial three-year collaborative programme of research and dissemination of knowledge and education between the School of Sport, Health and Exercise Science at the University of Portsmouth and the CF Warriors charity.

Central to this partnership is the promotion of the benefits of physical activity, exercise and good nutrition for people with cystic fibrosis. This involves conducting research studies to answer important questions raised by people with cystic fibrosis to help them engage in safe and effective lifelong exercise, as well as translating and publicising our collaborative research findings and other key educational sessions to people with cystic fibrosis through the charity network.

The 3 years, full-time, fully funded PhD studentship is being supervised by Dr Zoe Saynor, a world leading expert in exercise and cystic fibrosis, and an active member of the European Cystic Fibrosis Society exercise working group, alongside Dr Jo Corbett and Dr Anthony Shepherd. Additional clinical and research input will also come from clinical colleagues and an ongoing collaborative with the adult and paediatric cystic fibrosis services at the University Hospital Southampton NHS Foundation Trust.

The title of the PhD is:

Exercise and Nutrition for People with Cystic Fibrosis in the Modulator Era

We were delighted to welcome Lauren Clayton as the first PhD student funded by CF Warriors, who has joined the Physical Activity, Health and Rehabilitation Thematic Research Group, led by Dr Zoe Saynor. Over the next 3 years, Lauren will be working closely with Zoe, as well as colleagues in the Extreme Environments Thematic Research Group. This position also involves working closely with clinical colleagues (clinicians and physiotherapists) within the respiratory and paediatric departments at the University Hospital Southampton NHS Foundation Trust. The primary research environments are the exercise laboratories at the University of Portsmouth. The successful candidate will be working in a team with her supervisors and clinical staff and will be fully immersed in running clinical trials and the analyses of data.

The team are conducting research that has been informed by people with cystic fibrosis and aims to benefit people with cystic fibrosis. Specifically, the research undertaken aims to further our understanding on the topics of exercise and nutrition for people with cystic fibrosis as we transition into the modulator era, building on previous work conducted by the supervisory team.

Lauren will also be working closely with the charity to disseminate research findings to people with cystic fibrosis and their families.

As well as conducting research, Dr Zoe Saynor and the Lauren will collaborate closely with the charity and will be available over the 3 year program to deliver Q&A sessions through the CF Warriors platform. Both will also be available to deliver educational sessions.

PhD Programme of Research to commence in October 2021:

The schedule of research is as follows:

- Study 1** Evaluate the current hydration / salt requirement for people with CF (global)
- Study 2** Evaluate the experiences of people with CF who are now on modulators regarding their sweat responses, hydration and nutrition requirements. Also, evaluate current salt tablet use and nutritional supplement use
- Study 3** Laboratory study: Explore the thermo-physiological responses and markers of dehydration in people with cystic fibrosis during exercise in normal ambient conditions and exercise in the heat compared to healthy people – are these changed on modulators
- Study 4** Evaluate the knowledge regarding diet and exercise in people with CF
- Study 5** Assess the physical activity, glycaemic control and body composition of children and adults with cystic fibrosis
- Study 6** Laboratory study: Explore the effects of an alternative low-sugar high-calorie supplement versus currently prescribed supplements for people with cystic fibrosis on glycaemic control, fat oxidation at rest and during exercise and vascular health

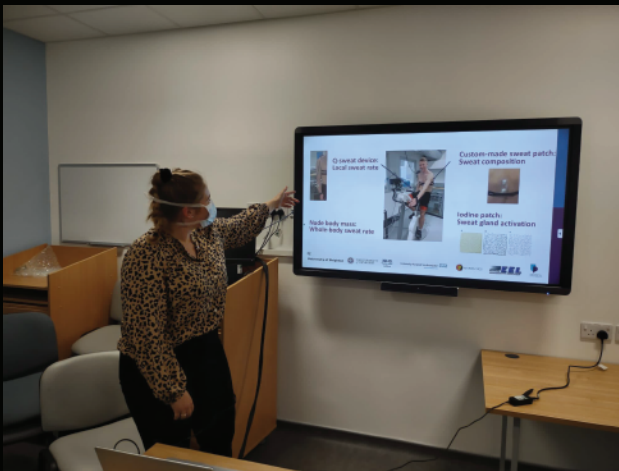
The initial grant of £25,200 was made in March 2021, to be followed by a further two payments of £26,400 in October 2022 and £27,600 in October 2023.

Summary of Progress Made by PhD Student Lauren Clayton
October 2021 - March 2022

0-3 months

- ✓ Inductions
- ✓ Settling in
- ✓ Meeting supervisors / PGRs / Staff
- ✓ Reading & learning on CF/CFTR modulators
- ✓ Formulating ideas for ethics protocol
- ✓ Attending CF clinics

COMPLETE



Next Steps

6-9 months

- Ethics protocol for study submitted with IRAS application
- Pilot testing for Study 2
- Up-skilling in protocol methods
- Start CPET testing at UHS
- Ethics protocol for Study 2 submitted
- Undertake placement with Dr Don Urquhart in Edinburgh
- Receive ethical approval for Study 1

In Progress

0-6 months

- ✓ Formulating ethics protocol for Study 1
- ✓ Formulating ethics protocol for Study 2
- ✓ £500 funding secured for placement
- ✓ Up-skilling in protocol methods
- ✓ Trip to the University of Brighton to meet with Neil Maxwell
- ✓ DEXA training
- ✓ CF Warriors first parents evening
- ✓ Networking with Southampton CF clinical team

COMPLETE



Next Steps

9-12 months

- Clinical CPET testing at UHS
- Receive ethical approval for Study 2
- Data collection for Study 1 & Study 2
- Formulating ethics protocol for Study 3
- Major Review

Future Progress

Study Titles

Study 1: Understand - CF

Observational study to UNDERSTAND the fitness, body composition, physical activity and sleep patterns in people with CF on CFTR modulator therapy compared to healthy controls

Study 2 – Heat - CF

Observational study to assess thermoregulatory response to exercise in HEAT at a fixed rate of metabolic heat production in people with CF on CFTR modulator therapies compared to healthy controls

Study 3 – Hydrate - CF

Observational study categorising sodium concentrations, hydration status, salt supplementation guideline perceptions

CF Warriors Parents' Evening

Our first Q&A evening took place at Portsmouth University, hosted by Josh Llewellyn-Jones, Dr Zoe Saynor and our PhD researcher Lauren Clayton. It was attended by families in the CF community to learn more about what sort of research we will be doing over the next 3 years, and how this research will directly impact the community on a global scale.



**THE MODERN WORLD OF
CYSTIC FIBROSIS**

Wednesday, February 2nd
LIVE at University of Portsmouth


Dr Zoe Saynor
PhD, MSc, BSc,
FHEA


Lauren Clayton
Researcher


Josh Llewellyn-Jones OBE

 UNIVERSITY OF PORTSMOUTH

 WARRIORS

Events

For a second year running, due to the Covid-19 pandemic, most of our events had to be postponed, but our community of supporters came to the rescue with some amazing challenges to inspire others, and to help raise awareness of the work the charity undertakes.

Warrior Games

Due to government restrictions, this year's event was unfortunately cancelled. A massive thank you to Jonny Gray and the rest of the team at the RAF for keeping us updated throughout the changing situation during lockdown. We hope to be back in 2022, bigger and better than ever!

Josh Llewellyn-Jones' Triad24

24hrs of Squats

24hr Run

24hrs of Burpees

Having not done any endurance challenges since 2019, Josh decided to attempt THREE 24hr challenges to make the Triad24. First off was the 24hr Squat challenge, followed by a 24hr Run around a Cardiff Bay circuit and the 24hrs of Burpees. Having completed his 24hr of squats, Josh had a few injuries to deal with, so when it came to the second challenge of the Triad, despite it being a flat circuit, Josh faced an uphill struggle from the start. One of his quads needed constant attention and was troubling Josh right from the first couple of laps, but he soldiered on for the full 24 hours. Due to the extent of his injuries following the run, the third challenge had to be abandoned, however, Josh still managed to raise over £7,000 for the charity.



Events

Bar 44 Taste of Spain Book Launch

We were so excited to be able to invite friends and supporters to an indoor event for the first time since 2019! The Bar 44 event was a huge success, and we were so grateful to Natalie Isaac, Tom & Owen Morgan for giving up so much of their time to help organise this event, and for entertaining the room with such great stories from all their experiences with the 44 brand. Thanks also to Blair Malins, The Duke of Wellington & their staff for giving us the venue to use and providing such fantastic service throughout the evening. The food & drink tasting was out of this world, and the Q&A afterwards was so entertaining. It certainly gave us a taste for more events future!



CF Warriors Weekend In Dover

The weekend started with a Black & White Ball at Bluebirds Function Rooms, which was a huge success and a great way to start the weekend. This was followed on the Sunday by a day of exercise activities at Dover Leisure Centre, organised by Kerrie Stoner and her squad of amazing PT staff and volunteers. Everyone did an amazing job of keeping the visitors entertained and the venue, where Josh did part of his 5Days4CF challenge were, as always, so accommodating with anything the charity needed throughout the day.



Events

Supporter Events

So many of our supporters answered the call to arms to help the charity this year, and we are so grateful to everyone who used their valuable time to help us. The Ditcham family, or Team Violet as we know them, organised a month-long event to travel 6,500 miles by any means possible (under their own steam), to raise money for the charity. Grace Angove ran every day for 65 days to support the charity! Logan walked up and down Pen-y-Fan in Wales to raise funds, he was only 5 years old and has cystic fibrosis – a true CF Warrior! Gwenda Goodman organised the Davenham Beavers to do a sponsored silence (no mean feat to get all those little ones to stay quiet!) Gianluca Palladino ran the Cardiff Half on behalf of CF Warriors. Our mini ambassador Enzo not only cheered Josh on during his Triad24 event, but yet again, took on his own challenge of riding his bike along a 50-mile trail! After being stopped due to bad weather and not one but two crashes, Enzo managed 32 miles and raised over £1,000 for CF Warriors!



Plans For The Future

- To further enhance our partnership with the University of Portsmouth and our Research Funding Program through development of clear communication material on findings of the research. Our PhD student Lauren has been keeping a diary, updating the charity on a regular basis, and much of this information can be found on our website news feed. We also update our social media with any exciting developments taking place on the research program
- We are looking to continue the Q&As with the Research Team to promote the Research Funding Program and the vision of the charity, as well as offer advice to CF families
- To increase the number of Warrior Packs sent out to CF Warriors around the world and to evolve the pack to include new items that will help motivate children to get active and stay healthy

Fundraising

- Despite the various restrictions across the country over the past year, thanks to our amazing community of supporters, we have helped to organise many outdoor events to raise awareness and funds for the charity.
- We have improved our fundraising strategy over the last 12 months and we are looking towards more grant funding applications, as well as several new events in the coming year which will help us to raise the necessary funds to meet our charitable obligations

Volunteers

A huge thank you to all the volunteers who made the last year such a memorable one and helped the charity to continue to raise awareness while the country was still in lockdown. This is not a full list of everyone who played a part in the charity throughout the year as several of our events were held remotely without our direct participation, but their involvement in the CF Warriors community is no less important than those that get special mention

- Emma Floyd
- Stuart Clarke
- Paul Madley
- Zoe Saynor & Iain Mars for supporting Josh so spectacularly through his 24hr squat challenge
- Carys Rees for all her incredibly hard work throughout the "Run" section of the Triad
- Rhys Jenkins, Stuart Clarke, Emily Madley and Caroline Sims for helping to get Josh round Cardiff Bay for the Triad24
- Kerrie Stoner & all the Team in Dover
- Dawn Llewellyn-Jones
- Adrian Llewellyn-Jones
- Anna & Ollie Gould

Supporters

A huge thank you to our network of supporters who have helped fund the charity throughout the year, and to all those who took up a challenge to help raise funds and awareness for the charity through the pandemic.

- Hopkins Law for their generous donation to the charity
- Team Violet Ditcham - Dani, Paul, David, Peter & the whole Ditcham family & friends who took part in the month long challenge
- Boots Cheshire
- Gwenda Goodman & the Davenham Beavers
- The Waterloo Foundation
- Karen Norris & the team at Brewin Dolphin
- Heather Walters
- Leanne Barter, Logan & Family
- The Blacksmith Arms Llanmaes Monday Night Quiz for their generous donation
- Iain Maynard
- Enzo & Family
- Paul Fears
- Jayne James & Loulou Boutique
- Jack Orledge
- Grace & Sam Angove
- Morgan Coxhead & Family
- Natalie Isaac, Tom & Owen Morgan & the Bar 44 Team for putting on an amazing event
- Blair Malins, the Duke of Wellington and Staff for providing their venue and services at no cost to the charity for our Bar 44 event!
- Kerrie Stoner & team for organising not one but two events over the course of one weekend! Special thanks to Marilyn Davidson, Carly Sykes-Blowers & Abby Chaston for all your help throughout the weekend in Dover
- Dover Leisure Centre
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- Elaine Milne
- The MDRT Foundation
- Lumen Financial
- Jemma & Tricia Morris - Derval Co (Denver Drilling)
- Dover Leisure Centre
- Adrian Llewellyn-Jones and The Mouse House
- The RAF – Jonny Gray, Kyle Young, Dot Perkins & the rest of the team for their continued support
- And not forgetting every single person that came to an event hosted by the charity, donated a raffle or auction prize to support CF Warriors, or donated to one of the many events that took place throughout the year. Without your support, we could not do what we do to help change the lives of these children living with this terrible disease.

Brief Statement of the Charity's Policy on Reserves

Cash reserves at 31 March 2021 were £26,805 in unrestricted funds. The initial research funding grant of £25,200 was made in March of 2021, to be followed by a further two payments of £26,400 in October 2022 and £27,600 in October 2023. To continue our Warrior Pack Program alongside this research funding, it is necessary to hold at least £25,000 to cover the running costs of the charity. This amount has reduced slightly from last year as we have a surplus of stock of several items in the Warrior Pack.

We are confident that with the number of plans we have in place for the coming year 2022-2023, our financial position will improve considerably, and we will be able to meet all our financial obligations regarding our Research Funding and the Warrior Pack Program in the years ahead.



CHARITY COMMISSION
FOR ENGLAND AND WALES

Independent examiner's report on the accounts

Section A Independent Examiner's Report

Report to the trustees/ members of	CF Warriors		
On accounts for the year ended	31 March 2022	Charity no (if any)	1178063
Set out on pages	The Trustee's Report and Accounts set out on pages 1 to 13 of the attached report.		

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31 March 2022.

Responsibilities and basis of report

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.

Signed:  **Date:** 26 January 2023

Name: Stephen Thomas

Relevant professional qualification(s) or body (if any): ACA

Address: Fair Oaks, 1 Pentre-poeth Road, Bassaleg, NP10 8LN



Charity Name CF Warriors	No (if any) 1178063
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CC16a

Receipts and payments accounts


For the period from	Period start date 01/04/2021	To	Period end date 31/03/2022
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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					
Donations	42,306	-	-	42,306	28,959
Event sponsorship and ticket sales	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	42,306	-	-	42,306	28,959
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	42,306	-	-	42,306	28,959
A3 Payments					
Grants to fund research	-	-	-	-	25,200
"CF Warrior" packs distributed free of charge	13,731	-	-	13,731	17,750
Employee costs	23,308	-	-	23,308	22,268
Office costs and fundraising expenses	7,286	-	-	7,286	4,632
Social media expenses	2,800	-	-	2,800	3,010
Legal and professional fees	1,176	-	-	1,176	1,873
Communication and IT expenses	2,086	-	-	2,086	1,847
Event expenses	861	-	-	861	-
Bank and payment processing fees	413	-	-	413	883
Insurance	341	-	-	341	318
Donations	-	-	-	-	150
	-	-	-	-	-
	-	-	-	-	-
Sub total	52,001	-	-	52,001	77,931
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	52,001	-	-	52,001	77,931
Net of receipts/(payments)	- 9,695	-	-	- 9,695	- 48,972
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	35,858	-	-	35,858	84,831
Cash funds this year end	26,163	-	-	26,163	35,858

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	Cash at bank	26,805	-	-
	Loan balance	- 642	-	-
		-	-	-
	Total cash funds	26,163	-	-
B2 Other monetary assets	Details			
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details		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)
	Other taxation and social security	Unrestricted	318	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval
		Josh Llewellyn-Jones	25/01/2023
	Paul Langmaid	Paul Langmaid	25/01/2023



WARRIORS

SUPPORTING CHILDREN WITH CYSTIC FIBROSIS

27F Vale Business Park
Llandow
Vale of Glamorgan
CF71 7PF

info@cfwarriors.org.uk

www.cfwarriors.org.uk

Charity No: 1178063

Introduction

It has been another challenging year for CF Warriors, with the impact of Covid-19 still being felt in Wales and across the globe, particularly affecting our community of families who have been dealing with a great deal of isolation and worry throughout these uncertain times. But there are a great many things to be hopeful for as restrictions have eased and life has begun to return to some form of normality. The charity has had to adapt once again to these challenges, to enable us to continue to provide our services to families living with cystic fibrosis in the UK and abroad. Restrictions in Wales have meant that nearly all the events we had hoped to host in the UK were abandoned, however it is with a great deal of gratitude that we can say our community of supporters found unique ways of helping us by organising so many of their own events to fundraise for the charity.

CF Warriors was founded to motivate, inspire and support children with cystic fibrosis on their journey to a longer, happier and healthier life. Our mission is to raise awareness of the benefits of sport and exercise to the CF community across the globe, through events, our Warrior Pack Program, and the publication of vital research funded by the charity.

The charity has begun its fully funded PhD studentship at the University of Portsmouth, and our PhD student Lauren Clayton has begun work on several studies, exploring the effects of not only exercise, but also nutrition, for people with cystic fibrosis in the modulator era. This is a huge step forward for the charity, one which we are so proud to be a part of, and we are incredibly excited to be helping the next generation of researchers explore the possibilities that the new modulator drugs available in the community are bringing.

Our Warrior Pack Program is also going strong and bringing some much-needed joy to families around the world. Our aim as always with this program is to include every child and ensure every request for a Warrior Pack, no matter where they are in the world, is met with a positive response, and no child is left behind.

Thank you to everyone who has supported the charity this year, we're looking forward to much more to come next year.

Mark Llewellyn-Jones
CEO

Report Of The Trustees For The Period 1st April 2021 To 31st March 2022

The Trustees present their report and financial statements for the period ended 31st March 2022.

Structure, Governance & Management

CF Warriors is a Charitable Incorporated Organisation, governed by its constitution as set out in the charity's governing document.

Board of Trustees

- Josh Llewellyn-Jones OBE - Chair
- Paul Langmaid CBE
- Steve Doyle
- Paul Floyd
- Jane Sharpe (Resigned 1/3/2022)

CF Warriors continues to recruit skilled and experienced trustees to the board to strengthen our team and drive our vision forward.

Management

- Mark Llewellyn-Jones - CEO

As CEO, Mark manages the day-to-day operations of the charity, ensuring that the CF Warriors charity delivers its vision and mission each week to the families that register with us. This includes all correspondence to the charity, managing the Warrior Pack Program, event organisation and fundraising, website and social media channels, and liaising with our Research Funding Partners at the University of Portsmouth.

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

For the public benefit, the relief of sickness and the preservation of health among people with cystic fibrosis by:

- (a) providing goods and/or equipment that can be used to aid the fitness and health of people with cystic fibrosis and support and practical advice for carrying out appropriate forms of exercise;
- (b) Providing funding for research into cystic fibrosis, in particular the treatment of cystic fibrosis and the effects of exercise on people with cystic fibrosis

What We Have Delivered This Year

CF Warriors has two main objectives that help deliver the vision of the charity.

Warrior Pack Program

Firstly, there is our Warrior Pack Program which is ongoing and is designed to inspire and motivate families to and show children suffering with cystic fibrosis that they are part of a larger community. This year we delivered 253 Warrior Packs to families around the world dealing with cystic fibrosis.

Research Funding

We have begun our very first Research Funding Program, which is 6 months into a 3-year project in partnership with the University of Portsmouth. The charity's aims through the research funding are to provide information to parents regarding nutrition, hydration and salt intake when their children are exercising or doing physical activities. The research is being undertaken by Lauren Clayton at the School of Sport, Health and Exercise Science at the University of Portsmouth. By funding this program, we are hoping to inspire the next generation of researchers to concentrate their efforts on cystic fibrosis, and by doing so, help families dealing with this disease to become more well informed in the nutritional problems facing children growing up with cystic fibrosis in the modulator era and break down some of the barriers that often cause children to stop using exercise as a means to staying fit and healthy.

Warrior Pack Program

We were able to continue this program throughout the pandemic despite lockdowns and government restrictions, and our Warrior Packs have been a huge success again this year, with us sending out over 250 packs to children from around the world, a very similar total to the previous year. We have also found that it has been a great way for us to connect with the CF Warriors community, to support children living with cystic fibrosis in what are incredibly lonely circumstances, particularly with the various restrictions that we have all had to endure over the last 12 months, and the uncertainty this has brought to the cf community.

The packs cost around £50 to produce, and the costs of sending them vary depending on which country the recipients live in, these costs range from £3 to £30. We also receive requests from many returning families for larger clothing as their children outgrow their Warrior Packs. It is our commitment to these children to meet these needs wherever possible as part of our core charitable objectives.

We receive so many kind messages from families expressing their gratitude, and many have become heavily involved in the charity, helping us either by fundraising at their own events, or giving up their valuable time volunteering for the charity at one of ours. We will always be grateful for all the hard work and time individuals give so readily to the charity to support our cause.

Research Funding

Partnership between the School of Sport, Health and Exercise Science (University of Portsmouth) and CF Warriors

This partnership is an initial three-year collaborative programme of research and dissemination of knowledge and education between the School of Sport, Health and Exercise Science at the University of Portsmouth and the CF Warriors charity.

Central to this partnership is the promotion of the benefits of physical activity, exercise and good nutrition for people with cystic fibrosis. This involves conducting research studies to answer important questions raised by people with cystic fibrosis to help them engage in safe and effective lifelong exercise, as well as translating and publicising our collaborative research findings and other key educational sessions to people with cystic fibrosis through the charity network.

The 3 years, full-time, fully funded PhD studentship is being supervised by Dr Zoe Saynor, a world leading expert in exercise and cystic fibrosis, and an active member of the European Cystic Fibrosis Society exercise working group, alongside Dr Jo Corbett and Dr Anthony Shepherd. Additional clinical and research input will also come from clinical colleagues and an ongoing collaborative with the adult and paediatric cystic fibrosis services at the University Hospital Southampton NHS Foundation Trust.

The title of the PhD is:

Exercise and Nutrition for People with Cystic Fibrosis in the Modulator Era

We were delighted to welcome Lauren Clayton as the first PhD student funded by CF Warriors, who joined the Physical Activity, Health and Rehabilitation Thematic Research Group, led by Dr Zoe Saynor.

Over the next 3 years, Lauren will be working closely Zoe, as well as colleagues in the Extreme Environments Thematic Research Group. This position also involves working closely with clinical colleagues (clinicians and physiotherapists) within the respiratory and paediatric departments at the University Hospital Southampton NHS Foundation Trust. The primary research environments are the exercise laboratories at the University of Portsmouth. The successful candidate will be working in a team with her supervisors and clinical staff and will be fully immersed in running clinical trials and the analyses of data.

The team are conducting research that has been informed by people with cystic fibrosis and aims to benefit people with cystic fibrosis. Specifically, the research undertaken aims to further our understanding on the topics of exercise and nutrition for people with cystic fibrosis as we transition into the modulator era, building on previous work conducted by the supervisory team.

Lauren will also be working closely with the charity to disseminate research findings to people with cystic fibrosis and their families.

As well as conducting research, Dr Zoe Saynor and the Lauren will collaborate closely with the charity and will be available over the 3 year program to deliver Q&A sessions through the CF Warriors platform. Both will also be available to deliver educational sessions.

PhD Programme of Research

The schedule of research:

Study 1 – Evaluate the current hydration / salt requirements for people with CF (global)

Study 2 – Evaluate the experiences of people with CF who are now on modulators regarding their sweat responses, hydration and nutrition requirements. Also, evaluate current salt tablet use and nutritional supplement use

Study 3 – Laboratory Study: Explore the thermo-physiological response and markers of dehydration in people with cystic fibrosis during exercise in normal ambient conditions and exercise in the heat compared to healthy people – are these changed on modulators

Study 4 – Evaluate the knowledge regarding diet and exercise in people with CF

Study 5 – Assess the physical activity, glycaemic control and body composition of children and adults with CF

Study 6 – Laboratory Study: Explore the effects of an alternative low-sugar high-calorie supplement versus currently prescribed supplements for people with CF on glycaemic control, fat oxidation at rest and during exercise and vascular health

The initial grant of £25,200 was made in March 2021, to be followed by a further two payments of £26,400 in October 2022 and £27,600 in October 2023.

Summary of Progress Made by PhD Student Lauren Clayton

October 2021 - March 2022

0-3 months

- ✓ Inductions
- ✓ Settling in
- ✓ Meeting supervisors / PGRs / Staff
- ✓ Reading & learning on CF/CFTR modulators
- ✓ Formulating ideas for ethics protocol
- ✓ Attending CF clinics

COMPLETE

0-6 months

- ✓ Formulating ethics protocol for Study 1
- ✓ Formulating ethics protocol for Study 2
- ✓ £500 funding secured for placement
- ✓ Up-skilling in protocol methods
- ✓ Trip to the University of Brighton to meet with Neil Maxwell
- ✓ DEXA training
- ✓ CF Warriors first parents evening
- ✓ Networking with Southampton CF clinical team

COMPLETE

Next Steps

6-9 months

- Ethics protocol for study submitted with IRAS application
- Pilot testing for Study 2
- Up-skilling in protocol methods
- Start CPET testing at UHS
- Ethics protocol for Study 2 submitted
- Undertake placement with Dr Don Urquhart in Edinburgh

Receive ethical approval for Study 1

In Progress

Next Steps

9-12 months

Clinical CPET testing at UHS

Receive ethical approval for Study 2

Data collection for Study 1 & Study 2

Formulating ethics protocol for Study 3

Major Review

Future Progress

Study Titles

Study 1: Understand - CF

Observational study to UNDERSTAND the fitness, body composition, physical activity and sleep patterns in people with CF on CFTR modulator therapy compared to healthy controls

Study 2 – Heat - CF

Observational study to assess thermoregulatory response to exercise in HEAT at a fixed rate of metabolic heat production in people with CF on CFTR modulator therapies compared to healthy controls

Study 3 – Hydrate - CF

Observational study categorising sodium concentrations, hydration status, salt supplementation guideline perceptions

CF Warriors Parents' Evening

Our first Q&A evening took place at Portsmouth University, hosted by Josh Llewellyn-Jones, Dr Zoe Saynor and our PhD researcher Lauren Clayton. It was attended by families in the CF community to learn more about what sort of research we will be doing over the next 3 years, and how this research will directly impact the community on a global scale.

Events

For a second year running, due to the Covid-19 pandemic, most of our events had to be postponed, but our community of supporters came to the rescue with some amazing challenges to inspire others, and to help raise awareness of the work the charity undertakes.

Warrior Games

Due to government restrictions, this year's event was unfortunately cancelled. A massive thank you to Jonny Gray and the rest of the team at the RAF for keeping us updated throughout the changing situation during lockdown. We hope to be back in 2022, bigger and better than ever!

Josh Llewellyn-Jones' Triad24

24hrs of Squats

24hr Run

24hrs of Burpees

Having not done any endurance challenges since 2019, Josh decided to attempt THREE 24hr challenges to make the Triad24. First off was the 24hr Squat challenge, followed by a 24hr Run around a Cardiff Bay circuit and the 24hrs of Burpees. Having completed his 24hr of squats, Josh had a few injuries to deal with, so when it came to the second challenge of the Triad, despite it being a flat circuit, Josh faced an uphill struggle from the start. One of his quads needed constant attention and was troubling Josh right from the first couple of laps, but he soldiered on for the full 24 hours. Due to the extent of his injuries following the run, the third challenge had to be abandoned, however, Josh still managed to raise over £7,000 for the charity.

Bar 44 Taste of Spain Book Launch

We were so excited to be able to invite friends and supporters to an indoor event for the first time since 2019! The Bar 44 event was a huge success, and we were so grateful to Natalie Isaac, Tom & Owen Morgan for giving up so much of their time to help organise this event, and for entertaining the room with such great stories from all their experiences with the 44 brand. Thanks also to Blair Malins, The Duke of Wellington & their staff for giving us the venue to use and providing such fantastic service throughout the evening. The food & drink tasting was out of this world, and the Q&A afterwards was so entertaining. It certainly gave us a taste for more events future!

CF Warriors Weekend In Dover

The weekend started with a Black & White Ball at Bluebirds Function Rooms, which was a huge success and a great way to start the weekend. This was followed on the Sunday by a day of exercise activities at Dover Leisure Centre, organised by Kerrie Stoner and her squad of amazing PT staff and volunteers. Everyone did an amazing job of keeping the visitors entertained and the venue, where Josh did part of his 5Days4CF challenge were, as always, so accommodating with anything the charity needed throughout the day.

Supporter Events

So many of our supporters answered the call to arms to help the charity this year, and we are so grateful to everyone who used their valuable time to help us. The Ditcham family, or Team Violet as we know them, organised a month-long event to travel 6,500 miles by any means possible (under their own steam), to raise money for the charity. Grace Angove ran every day for 65 days to support the charity! Logan walked up and down Pen-y-Fan in Wales to raise funds, he was only 5 years old and has cystic fibrosis – a true CF Warrior! Gwenda Goodman organised the Davenham Beavers to do a sponsored silence (no mean feat to get all those little ones to stay quiet!) Gianluca Palladino ran the Cardiff Half on behalf of CF Warriors. Our mini ambassador Enzo not only cheered Josh on during his Triad24 event, but yet again, took on his own challenge of riding his bike along a 50-mile trail! After being stopped due to bad weather and not one but two crashes, Enzo managed 32 miles and raised over £1,000 for CF Warriors!

Plans For The Future

- To further enhance our partnership with the University of Portsmouth and our Research Funding Program through development of clear communication material on findings of the research. Our PhD student Lauren has been keeping a diary, updating the charity on a regular basis, and much of this information can be found on our website news feed. We also update our social media with any exciting developments taking place on the research program
- We are looking to continue the Q&As with the Research Team to promote the Research Funding Program and the vision of the charity, as well as offer advice to CF families

- To increase the number of Warrior Packs sent out to CF Warriors around the world and to evolve the pack to include new items that will help motivate children to get active and stay healthy
- Continue to raise the profile of CF Warriors, particularly in the UK by holding or attending more events, hold speaking engagements and continuing

Fundraising

- We understand that we have serious competition for funding from so many other charities in the UK, and so we have improved our fundraising strategy, planned more events for the next 12 months, and we have increased the number of grant applications planned for the next year to improve our fundraising capabilities, and capitalise on our network of supporters, as well as increase this network in the coming months.
- Despite the various restrictions across the country over the past year, thanks to our amazing community of supporters, we have helped to organise many outdoor events to raise awareness and fundraise for the charity. We are hoping that many of these events will become annual occasions for the charity, which will be added to our calendar of events and improve our fundraising efforts.

Volunteers

A huge thank you to all the volunteers who made the last year such a memorable one and helped the charity to continue to raise awareness while the country was still in lockdown. This is not a full list of everyone who played a part in the charity throughout the year as several of our events were held remotely without our direct participation, but their involvement in the CF Warriors community is no less important than those that get special mention

- Emma Floyd
- Dawn Llewellyn-Jones
- Caroline Sims
- Emily Madley
- Paul Madley
- Adrian Llewellyn-Jones
- Anna & Ollie Gould
- Zoe Saynor & Iain Mars for supporting Josh so spectacularly through his 24hr squat challenge
- Carys Rees for all her incredibly hard work throughout the “Run” section of the Triad24 in Cardiff Bay
- Stuart Clarke & Rhys Jenkins for helping to get Josh round Cardiff Bay for the Triad24

Supporters

A huge thank you to our network of supporters who have helped fund the charity throughout the year, and to all those who took up a challenge to help raise funds and awareness for the charity through the pandemic.

- Hopkins Law for their generous donation to the charity
- Team Violet Ditcham - Dani, David, Peter & the whole Ditcham family & friends who took part in the month-long challenge
- Boots Cheshire

- Enzo, Alec Gee, Jules Gibson and crew for supporting the charity on so many occasions over the last 12 months
- Gwenda Goodman & the Davenham Beavers
- The Waterloo Foundation
- Karen Norris & the team at Brewin Dolphin
- Heather Walters
- Leanne Barter, Logan & Family – absolutely amazing effort climbing Pen-y-Fan this year!
- The Blacksmith Arms Llanmaes Monday Night Quiz for their generous donation
- Iain Maynard
- Enzo & Family
- Jayne James & Loulou Boutique
- Lo Lounge Café and Bar, Cardiff Bay
- Jack Orledge
- Grace & Sam Angove
- Morgan Coxhead & Family
- Natalie Isaac, Tom & Owen Morgan & the Bar 44 Team for putting on an amazing event
- Blair Malins, the Duke of Wellington and Staff for providing their venue and services at no cost to the charity for our Bar 44 event!
- Kerrie Stoner & team for organising not one but two events over the course of one weekend! Special thanks to Marilyn Davidson, Carly Sykes-Blowers & Abby Chaston for all your help throughout the weekend in Dover
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- Jemma & Tricia Morris - Derval Co (Denver Drilling)
- Dover Leisure Centre
- Adrian Llewellyn-Jones and The Mouse House
- The RAF – Jonny Gray, Kyle Young, Dot Perkins & the rest of the team for their continued support

And not forgetting every single person that came to an event hosted by the charity, donated a raffle or auction prize to support CF Warriors, or donated to one of the many events that took place throughout the year. Without your support, we could not do what we do to help change the lives of these children living with this terrible disease.

Brief Statement of the charity's policy on reserves

Cash reserves at 31 March 2021 were £26,805 in unrestricted funds

The initial research funding grant of £25,200 was made in March of 2021, to be followed by a further two payments of £26,400 in October 2022 and £27,600 in October 2023. To continue our Warrior Pack Program

alongside this research funding, it is necessary to hold at least £25,000 to

cover the running costs of the charity. This amount has reduced slightly from last year as we have a surplus of stock of several items in the Warrior Pack. We are confident that with the number of plans we have in place for the coming year 2022-2023, our financial position will improve considerably, and we will be able to meet all our financial obligations regarding our Research Funding and the Warrior Pack Program in the years ahead.

CF WARRIORS

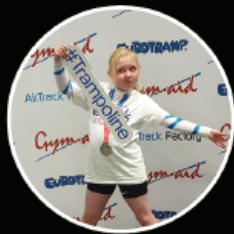
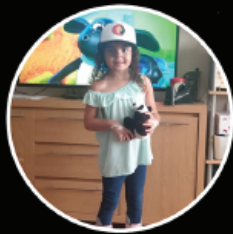
England & Wales - Charity number 1178063

Accounts



WARRIORS
SUPPORTING CHILDREN WITH CYSTIC FIBROSIS

ANNUAL REPORT
2020 - 2021



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Introduction

CF Warriors was founded to motivate, inspire and support children with cystic fibrosis on their journey to a longer, happier and healthier life. Our mission is to raise awareness of the benefits of sport and exercise to the CF community across the globe, through events, our Warrior Pack Program, and the publication of vital research funded by the charity.

In March 2020 the world became a different place, and the UK was put into lockdown, which made it incredibly difficult for everyone in the country, particularly people dealing with cystic fibrosis.

Fortunately, we have been able to continue to operate the charity, and to support families dealing with cystic fibrosis by sending out Warrior Packs to over 250 CF Warriors, not just in the UK but around the world. In October of 2020 we moved into a new commercial unit, as we needed more space for all the new Warrior Pack goodies, and event

equipment we had acquired over the past 2 years, which has given us a base to work from and room to expand.

The charity is so excited to have begun our partnership with the University of Portsmouth and has agreed to a 3-year collaborative programme of research and dissemination of

knowledge to promote the benefits of

physical activity, exercise and good nutrition for people with cystic fibrosis.

It is the hope of the charity that we have been able to bring some light in the dark times of this pandemic, and we will continue to do so for as long as we can. Our aim is to reach every child born

with this terrible disease, to help them see that they are part of a larger

community who are there to support each other through the hardest of times.

With the help of our friends and supporters who have been so generous with their time throughout the year, we hope to reach even more children in the coming years and build upon what is already

a wonderful

community.



Mark Llewellyn-Jones

CEO

Report Of The Trustees For The Period 1st April 2020 To 31st March 2021

The Trustees present their report and financial statements for the period ended 31st March 2021

Structure, Governance & Management

CF Warriors is a Charitable Incorporated Organisation, governed by its constitution as set out in the charity's governing document.

Board of Trustees

- Josh Llewellyn-Jones OBE - Chair
- Paul Langmaid CBE
- Steve Doyle
- Jane Sharpe
- Paul Floyd

CF Warriors continues to recruit skilled and experienced trustees to the board to strengthen our team and drive our vision forward.

Management

- Mark Llewellyn-Jones - CEO

As CEO, Mark manages the day-to-day operations of the charity, ensuring that the CF Warriors charity delivers its vision and mission each week to the families that register with us. This includes all correspondence to the charity, managing the Warrior Pack Program, event organisation and fundraising, website and social media channels, and liaising with our Research Funding Partners at the University of Portsmouth.

What We Have Delivered This Year

CF Warriors has two main objectives that help deliver the vision of the charity.

Warrior Pack Program

Firstly, there is our Warrior Pack Program which is ongoing and is designed to inspire, motivate and show children suffering with cystic fibrosis that they are part of a larger community. This year we delivered 258 Warrior Packs to families around the world dealing with cystic fibrosis.

Research Funding

Secondly, there is our Research Funding Program, which has received its first round of funding - £25,200 - as part of a 3-year project in partnership with the University of Portsmouth. The charity's aims through the research funding are to provide information to parents regarding nutrition, hydration and salt intake when their children are exercising or doing physical activities. We also want to help remove some of the barriers that can often cause children to stop using exercise, or any physical activity, as a way of staying fit and healthy. For example, by targeting some of the nutritional problems CF sufferers have to deal with, it is our hope that this research will give an insight into the effects of good nutrition on combatting the negative impacts of this disease, and help them engage in safe and effective lifelong exercise.

Warrior Pack Program

Our Warrior Pack program has been very popular over the last 12 months, and we have continued to develop & distribute our Packs, including more items that we hope children will find useful, help them feel like part of a larger community and motivate them to stay as fit and healthy as possible.

We have sent out over 250 Warrior Packs to members of the CF community this year, from countries all over the world, a 20% increase on last year. The packs cost £50 to produce, and the costs of sending them vary depending on which country the recipients live in, these costs range from £3 to £30. We also receive requests from many returning families for larger clothing as their children outgrow their Warrior Packs. It is our commitment to these children to meet these needs wherever possible as part of our core charitable objectives.

We know from the many messages we receive on a weekly basis what these packs mean to families and children growing up with cystic fibrosis, and we aim to respond to every request positively so that every child born with this disease can be included in the community.



Research Funding

Partnership between the School of Sport, Health and Exercise Science (University of Portsmouth) and the CF Warriors

This partnership is an initial three-year collaborative programme of research and dissemination of knowledge and education between the School of Sport, Health and Exercise Science at the University of Portsmouth and the CF Warriors charity.

Central to this partnership is the promotion of the benefits of physical activity, exercise and good nutrition for people with cystic fibrosis. This involves conducting research studies to answer important questions raised by people with cystic fibrosis to help them engage in safe and effective lifelong exercise, as well as translating and publicising our collaborative research findings and other key educational sessions to people with cystic fibrosis through the charity network.

The 3 years, full-time, fully funded PhD studentship is being supervised by Dr Zoe Saynor, a world leading expert in exercise and cystic fibrosis, and an active member of the European Cystic Fibrosis Society exercise working group, alongside Dr Jo Corbett and Dr Anthony Shepherd. Additional clinical and research input will also come from clinical colleagues and an ongoing collaborative with the adult and paediatric cystic fibrosis services at the University Hospital Southampton NHS Foundation Trust.

The title of the PhD is:

Exercise and Nutrition for People with Cystic Fibrosis in the Modulator Era

The successful candidate will join the Physical Activity, Health and Rehabilitation Thematic Research Group, led by Dr Zoe Saynor, whilst also working closely with colleagues in the Extreme Environments Thematic Research Group. This position also involves working closely with clinical colleagues (clinicians and physiotherapists) within the respiratory and paediatric departments at the University Hospital Southampton NHS Foundation Trust. The primary research environments are the exercise laboratories at the University of Portsmouth. The successful candidate will be working in a team with her supervisors and clinical staff and will be fully immersed in running clinical trials and the analyses of data.

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They are expected to conduct research that has been informed by people with cystic fibrosis and aims to benefit people with cystic fibrosis. Specifically, the research undertaken aims to further our understanding on the topics of exercise and nutrition for people with cystic fibrosis as we transition into the modulator era, building on previous work conducted by the supervisory team.

This PhD studentship is an exciting opportunity in partnership with the Charity, and the student will also be working closely with the charity to disseminate research findings to people with cystic fibrosis and their families.

As well as conducting research, Dr Zoe Saynor and the PhD student will collaborate closely with the charity and will be available to deliver monthly Q&A sessions through the CF Warriors platform. Both will also be available to deliver educational sessions. Josh Llewellyn-Jones has agreed to provide a talk at the University of Portsmouth free of charge once a year as part of the program. Dr Zoe Saynor will be an advocate for the charity and available when needed for talks / Q&As free of charge.

PhD Programme of Research to commence in October 2021:

The schedule of research is as follows:

- Study 1** Evaluate the current hydration / salt requirement for people with CF (global)

- Study 2** Evaluate the experiences of people with CF who are now on modulators regarding their sweat responses, hydration and nutrition requirements. Also, evaluate current salt tablet use and nutritional supplement use

- Study 3** Laboratory study: Explore the thermo-physiological responses and markers of dehydration in people with cystic fibrosis during exercise in normal ambient conditions and exercise in the heat compared to healthy people – are these changed on modulators

- Study 4** Evaluate the knowledge regarding diet and exercise in people with CF

- Study 5** Assess the physical activity, glycaemic control and body composition of children and adults with cystic fibrosis

- Study 6** Laboratory study: Explore the effects of an alternative low-sugar high-calorie supplement versus currently prescribed supplements for people with cystic fibrosis on glycaemic control, fat oxidation at rest and during exercise and vascular health

The initial grant of £25,200 was made this year, to be followed by a further two payments of £26,400 in October 2022 and £27,600 in October 2023.

Events

Unfortunately, due to the pandemic, group events like the Warrior Games, or any dinners that we were planning, were put on hold. However, the CF Warriors community didn't let us down, and came out in force to do their own challenges to help us raise money and awareness for the charity.

Warrior Games

This year's event was unfortunately cancelled but we still had donations from some amazing supporters who also helped raise awareness for the charity through some of their social media content where they talked about the charity. Massive thank you to Jonny Gray and the rest of the team at the RAF for keeping us updated throughout the changing situation during lockdown. We hope to be back in 2022!

Ben Mudge - £903 - Cycle / Assault Bike Marathon Challenge

Ben, who has cystic fibrosis, wanted to take on a challenge he could do while self-isolating, so decided what better way than to do a marathon on his home bike. However, in true CF Warrior style, he wanted to push himself and show what he could do so did a marathon x2.6 while helping the charity to raise awareness and funds.

Rhys Jenkins - Wales Coast Path - £2,091

Over the course of 3 weeks in August 2020, Rhys Jenkins, an ultra-marathon runner from Cardiff, took on 870 miles of the Wales Coast Path. Starting in the North and running South, he covered every inch of the world's first ever coastal path. The journey began in Chester and ended in Chepstow.

To give you a sense of the challenge – it is the equivalent of running 33.2 marathons and climbing the height of Everest 4.5 times."

Events

Next Gen Planners - 24-hour Global Commute - £2,738

The 24-Hour Global Commute combined two things:

- Raising money for 2 charities via charity challenges from the NextGen Planners Community;
- Speaking with financial planners from all around the globe.

Their two chosen charities were CF Warriors and Stroke Association. They chose these charities because their loyal contributors to the Next Gen Planners Morning Commute have been directly affected by the causes that these charities strive to help.

Some of the challenges that their brave volunteers took part in included climbing Mount Everest (on the stairs), rowing the English Channel (in the garden) and more socially distanced endurance-style challenges. All to promote the importance of sport and exercise to stay fit and healthy.

Linc Cymru - 870 Challenge - £871

Linc Cymru's team of colleagues had a plan to cover 870 miles – the length of the Wales Coastal Path and raise £870 for CF Warriors.

At a time when exercise and fresh air are proving to be vital for everyone's wellbeing, they thought that this would be a perfect time for a physical challenge in the great outdoors, (in their local area of course!)

Their plan allowed them to cover as many miles as they want, whether it was 2, 5 or even 10 miles; it all counted and would help them reach their goal. The idea was that they could walk, run, cycle or even get creative – 8 minutes on a trampoline is equivalent to 1 mile, and half hour of dancing during a home disco was 2 miles of exercise.

Events

Cooper Sheppard – Cooper’s CF 65 Challenge - £565

9-year-old Cooper, who has a younger brother with cystic fibrosis, had been taking part in exercising with Josh at 7pm every evening, and enjoyed the classes so much that he decided he would like to do something to help fundraise for CF Warriors, so he decided to do a challenge and came up with his CF 65 Challenge.

His challenge was to do 65 sit ups, 65 mountain climbers, 65 jumping Jack's, a 65-minute bounce on the trampoline and 65 squats – all to be completed in 2.5 hours! He helped the charity raise some much-needed funds while also helping to raise awareness and inspire people who follow the charity to stay active during the pandemic

Enzo Gibson – Cinder Track Challenge - £1,380

Enzo, one of our CF Warriors (and Alec!) rode his new bike from Whitby to Scarborough to raise some funds for the charity, on the Cinder Track, a 21.5-mile route, which is pretty big for a 6-year-old! They actually managed 22.6 miles in just under 3.5 hours!

Kerrie Stoner - Home Lockdown Workouts & Bootcamps - £1,437

Kerrie started her free home lockdown workouts to help keep people motivated and moving at a very uncertain time for everyone. We all know how important it is to keep the body and mind active where possible, and her help and support had huge benefits for everyone involved. We had so many wonderful messages regarding all the hard work Kerrie put into each workout.

As some of the restrictions were removed after the initial lockdown, Kerrie started her outdoor bootcamps to get people exercising together and raised so much awareness for the importance of exercise not only physically, but also for everyone’s mental wellbeing.

Events

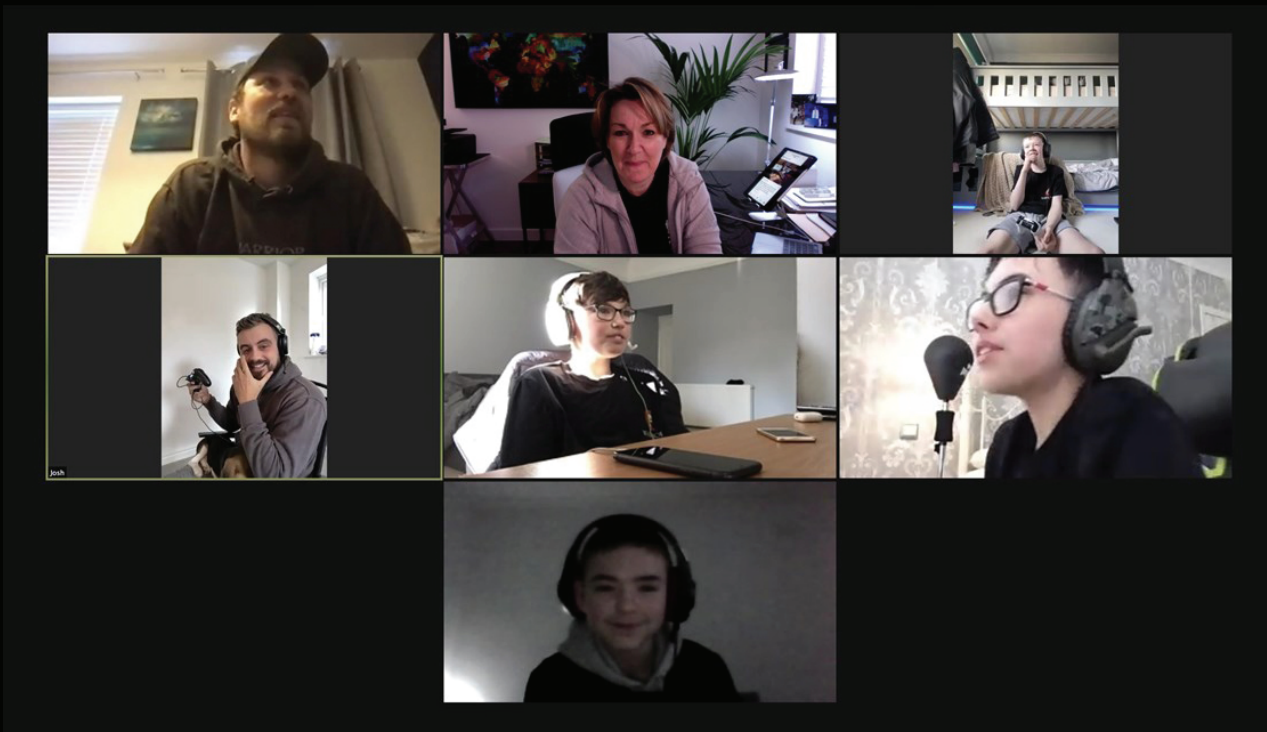
Elaine Milne – X-Box Warriors - £1,447

Elaine persuaded 4 boys from Scotland to team up in the last few hours of lockdown before they went back to school, to game for 16 hours to raise awareness CF Warriors and they didn't disappoint, gaming all the way through the night to help raise money for the charity, with help from their mums and Elaine!

Josh Llewellyn-Jones

Instagram & Facebook workouts during lockdown to help get children with cystic fibrosis (and others) up and exercising for at least 15 minutes every day at 7pm

Christmas Advent – Workouts with CF Warriors online throughout December to motivate children to keep fit and active in the lead up to Christmas



Plans For The Future

- To enhance our partnership with the University of Portsmouth and our Research Funding Program through development of clear communication material on findings of the research
- Q&As with Research Team to promote the Research Funding Program and the vision of the charity, as well as offer advice to CF families
- Further develop our Warrior Packs and increase the number of packs sent out to CF Warriors around the world
- To develop a clear fundraising strategy to help the charity achieve its goals over the next 2 years
- To develop clear communication material of who we are and what we do as a charity
- To develop relationships with local CF units to provide information on what we do and Warrior Packs to children with cystic fibrosis
- To plan several fundraising events to help raise awareness of the charity's vision"

Volunteers

A huge thank you to all the volunteers who made the last year such a memorable one and helped the charity to continue to raise awareness while the country was still in lockdown. This is not a full list of everyone who played a part in the charity throughout the year as several of our events were held remotely without our direct participation, but their involvement in the CF Warriors community is no less important than those that get special mention

- Emma Floyd
- Georgina Madley
- Emily Madley
- Paul Madley
- Dawn Llewellyn-Jones
- Cerys Jenkins & Team Rokman
- All the X-Box Warrior mums
- Kerrie Stoner & all the Staff at Dover Leisure Centre

Supporters

A huge thank you to our network of supporters who have helped fund the charity throughout the year, and to all those who took up a challenge to help raise funds and awareness for the charity through the pandemic.

- Linc Cymru and all their team
- Hopkins Law for their generous donation to the charity
- Elaine Milne for not only supporting the charity with a fundraising event and grant funding, but also for helping a local family with the use of a caravan (purchased by Elaine herself!) during lockdown when a CF Warrior's father had to isolate from the family because of work
- The MDRT Foundation for their grant funding program
- The Waterloo Foundation for their grant contribution to our Warrior Pack Program
- Karen Norris & the team at Brewin Dolphin
- Morgan Coxhead & Family – For taking on his very own Ironman Challenge for CF Warriors
- Rachel Davies – For using Josh's 7pm workouts as a reason to help us raise money and awareness
- Kerrie Stoner for everything!
- The Gibson Family
- Jessica Buss
- Jack Orledge
- Jon Westwood
- Lumen Financial
- Denva Co (Denver Drilling)
- Kerrie Stoner and Dover Leisure Centre
- Adrian Llewellyn-Jones and The Mouse House for their generous donation to the charity
- Steve Martin and Smart Finance for nominating our charity for the Next Gen Planners Event
- Michelle Martin, whose Team Carlos managed to raise over £1,500 for the charity despite the Warrior Games being cancelled!
- RAF St Athan – Jonny Gray, Kyle Young, Dot Perkins & the rest of the team



CHARITY COMMISSION
FOR ENGLAND AND WALES

**Independent examiner's report on the
accounts**

Section A Independent Examiner's Report

Report to the trustees/ members of	CF Warriors		
On accounts for the year ended	31 March 2021	Charity no (if any)	1178063
Set out on pages	The Trustee's Report and Accounts set out on pages 1 to 13		

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31 March 2021

Responsibilities and
basis of report

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.

Signed:  Date: 25 January 2022

Name: Stephen Thomas

Relevant professional qualification(s) or body (if any): ACA

Address: Fairoaks, 1 Pentre-poeth Road, Bassaleg, NP10 8LN



Charity Name CF Warriors			No (if any) 1178063		CC16a
Receipts and payments accounts					
For the period from	Period start date 01/04/2020	To	Period end date 31/03/2021		

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					
Donations	28,959	-	-	28,959	97,002
Event sponsorship and ticket sales	-	-	-	-	9,762
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	28,959	-	-	28,959	106,763
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	28,959	-	-	28,959	106,763
A3 Payments					
Grants to fund research	25,200	-	-	25,200	-
"CF Warrior" packs distributed free of charge	17,750	-	-	17,750	13,963
Employee costs	22,268	-	-	22,268	8,746
Office costs and fundraising expenses	4,632	-	-	4,632	22,577
Social media expenses	3,010	-	-	3,010	1,750
Legal and professional fees	1,873	-	-	1,873	1,128
Communication and IT expenses	1,847	-	-	1,847	822
Bank and payment processing fees	883	-	-	883	1,010
Insurance	318	-	-	318	-
Donations	150	-	-	150	8,200
	-	-	-	-	-
	-	-	-	-	-
Sub total	77,931	-	-	77,931	58,196
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	77,931	-	-	77,931	58,196
Net of receipts/(payments)	48,972	-	-	48,972	48,567
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	84,831	-	-	84,831	36,264
Cash funds this year end	35,858	-	-	35,858	84,831

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	Cash at bank	36,500	-	-
	Loan balance	- 642	-	-
		-	-	-
	Total cash funds	35,858	-	-
	(agree balances with receipts and payment: account(s))	OK	OK	OK


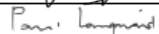
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities	Other taxation and social security	Unrestricted	639	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
	Josh Llewellyn-Jones OBE	25/1/2022
	Paul Langmaid CBE	25/1/2022



WARRIORS

SUPPORTING CHILDREN WITH CYSTIC FIBROSIS

27F Vale Business Park
Llandow
Vale of Glamorgan
CF71 7PF

info@cfwarriors.org.uk

www.cfwarriors.org.uk

Charity No: 1178063

Trustees' Annual Report for the period

	Period start date			Period end date			
From	1	April	2020	To	31	March	2021

Section A Reference and administration details

Charity name

CF Warriors

Other names charity is known by

Registered charity number (if any)

1178063

Charity's principal address

Unit 27F Vale Business Park	
Llandow	
Vale of Glamorgan	
Postcode	CF71 7PF

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	Josh Llewellyn-Jones OBE	Chair	Acted whole period	
2	Paul Langmaid CBE		Acted whole period	
3	Steve Doyle		Acted whole period	
4	Jane Sharpe		Acted whole period	
5	Paul Floyd		Acted whole period	
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)

Mark Llewellyn-Jones – Chief Executive Officer

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 – Charitable incorporated organisation
Trustee selection methods (eg. appointed by, elected by)	<p>(1) Apart from the first charity trustees, every trustee must be appointed [for a term of 3 years] by a resolution passed at a properly convened meeting of the charity trustees</p> <p>(2) In selecting individuals for appointment as charity trustees, the charity trustees must have regard to the skills, knowledge and experience needed for the effective administration of the CIO</p>

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.

CF Warriors continues to recruit skilled and experienced trustees to the board to strengthen our team and drive our vision forward.

As CEO, Mark manages the day-to-day operations of the charity, ensuring that the **CF Warriors** charity delivers its vision and mission each week to the families that register with us. This includes all correspondence to the charity, managing the Warrior Pack Program, event organisation and fundraising, website and social media channels, and liaising with our Research Funding Partners at the University of Portsmouth.

Section C Objectives and activities

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

For the public benefit, the relief of sickness and the preservation of health among people with cystic fibrosis by:

- (a) providing goods and/or equipment that can be used to aid the fitness and health of people with cystic fibrosis and support and practical advice for carrying out appropriate forms of exercise;
- (b) Providing funding for research into cystic fibrosis, in particular the treatment of cystic fibrosis and the effects of exercise on people with cystic fibrosis

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)

Events

Unfortunately, due to the pandemic, group events like the Warrior Games, or any dinners that we were planning, were put on hold. However, the CF Warriors community didn't let us down, and came out in force to do their own challenges to help us raise money and awareness for the charity.

Warrior Games

This year's event was unfortunately cancelled but we still had donations from some amazing supporters who also helped raise awareness for the charity through some of their social media content where they talked about the charity. Massive thank you to Jonny Gray and the rest of the team at the RAF for keeping us updated throughout the changing situation during lockdown. We hope to be back in 2022!

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everyone's wellbeing, they thought that this would be a perfect time for a physical challenge in the great outdoors, (in their local area of course!) Their plan allowed them to cover as many miles as they want, whether it was 2, 5 or even 10 miles; it all counted and would help them reach their goal. The idea was that they could walk, run, cycle or even get creative – 8 minutes on a trampoline is equivalent to 1 mile, and half hour of dancing during a home disco was 2 miles of exercise.

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Josh Llewellyn-Jones

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- Q&As with Research Team to promote the Research Funding Program and the vision of the charity, as well as offer advice to CF families
- Further develop our Warrior Packs and increase the number of packs sent out to CF Warriors around the world
- To develop a clear fundraising strategy to help the charity achieve its goals over the next 2 years
- To develop clear communication material of who we are and what we do as a charity
- To develop relationships with local CF units to provide information on what we do and Warrior Packs to children with cystic fibrosis
- To plan several fundraising events to help raise awareness of the charity's vision

Additional details of objectives and activities (Optional information)

Volunteers

A huge thank you to all the volunteers who made the last year such a memorable one and helped the charity to continue to raise awareness while the country was still in lockdown. This is not a full list of everyone who played a part in the charity throughout the year as several of our events were held remotely without our direct participation, but their involvement in the CF Warriors community is no less important than those that get special mention

- Emma Floyd
- Georgina Madley
- Emily Madley
- Paul Madley
- Dawn Llewellyn-Jones
- Cerys Jenkins & Team Rokman
- All the X-Box Warrior mums
- Kerrie Stoner & all the Staff at Dover Leisure Centre

Supporters

A huge thank you to our network of supporters who have helped fund the charity throughout the year, and to all those who took up a challenge to help raise funds and awareness for the charity through the pandemic.

- Linc Cymru and all their team
- Hopkins Law for their generous donation to the charity
- Elaine Milne for not only supporting the charity with a fundraising event and grant funding, but also for helping a local family with the use of a caravan (purchased by Elaine herself!) during lockdown when a CF Warrior's father had to isolate from the family because of work
- The MDRT Foundation for their grant funding program
- The Waterloo Foundation for their grant contribution to our Warrior Pack Program
- Karen Norris & the team at Brewin Dolphin
- Morgan Coxhead & Family – For taking on his very own Ironman Challenge for CF Warriors
- Rachel Davies – For using Josh's 7pm workouts as a reason to help us raise money and awareness
- Kerrie Stoner for everything!
- The Gibson Family
- Jessica Buss
- Jack Orledge
- Jon Westwood & Miranda McGinn
- Lumen Financial
- Derval Co (Denver Drilling)
- Kerrie Stoner and Dover Leisure Centre
- Adrian Llewellyn-Jones and The Mouse House for their generous donation to the charity
- Steve Martin and Smart Finance for nominating our charity for the Next Gen Planners Event
- Michelle Martin, whose Team Carlos managed to raise over £1,500 for the charity despite the Warrior Games being cancelled!
- RAF St Athan – Jonny Gray, Kyle Young, Dot Perkins & the rest of the team

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

Introduction

CF Warriors was founded to motivate, inspire and support children with cystic fibrosis on their journey to a longer, happier and healthier life. Our mission is to raise awareness of the benefits of sport and exercise to the CF community across the globe, through events, our Warrior Pack Program, and the publication of vital research funded by the charity. In March 2020 the world became a different place, and the UK was put into lockdown, which made it incredibly difficult for everyone in the country, particularly people dealing with cystic fibrosis. Fortunately, we have been able to continue to operate the charity, and to support families dealing with cystic fibrosis by sending out Warrior Packs to over 250 CF Warriors, not just in the UK but around the world. In October of 2020 we moved into a new commercial unit, as we needed more space for all the new Warrior Pack goodies, and event equipment we had acquired over the past 2 years, which has given us a base to work from and room to expand.

The charity is so excited to have begun our partnership with the University of Portsmouth and has agreed to a 3-year collaborative programme of research and dissemination of knowledge to promote the benefits of physical activity, exercise and good nutrition for people with cystic fibrosis.

It is the hope of the charity that we have been able to bring some light in the dark times of this pandemic, and we will continue to do so for as long as we can. Our aim is to reach every child born with this terrible disease, to help them see that they are part of a larger community who are there to support each other through the hardest of times.

With the help of our friends and supporters who have been so generous with their time throughout the year, we hope to reach even more children in the coming years and build upon what is already a wonderful community.

Mark Llewellyn-Jones
CEO

What We Have Delivered This Year

CF Warriors has two main objectives that help deliver the vision of the charity.

- Firstly, there is our **Warrior Pack Program** which is ongoing and is designed to inspire, motivate and show children suffering with cystic fibrosis that they are part of a larger community. This year we delivered **258 Warrior Packs** to families around the world dealing with cystic fibrosis.
- Secondly, there is our **Research Funding Program**, which has received its first round of funding - **£25,200** - as part of a 3-year project in partnership with the University of Portsmouth. The charity's aims through the research funding are to provide information to parents regarding nutrition, hydration and salt intake when their children are exercising or doing physical activities. We also want to help remove some of the barriers that can often cause children to stop using exercise, or any physical activity, as a way of staying fit and healthy. For example, by targeting some of the nutritional problems CF sufferers have to deal with, it is our hope that this research will give an insight into the effects of good nutrition on combatting the negative impacts of this disease, and help them engage in safe and effective lifelong exercise.

Warrior Pack Program

Our Warrior Pack program has been very popular over the last 12 months, and we have continued to develop & distribute our Packs, including more items that we hope children will find useful, help them feel like part of a larger community and motivate them to stay as fit and healthy as possible.

We have sent out over 250 Warrior Packs to members of the CF community this year, from countries all over the world, a 20% increase on last year. The packs cost £50 to produce, and the costs of sending them vary depending on which country the recipients live in, these costs range from £3 to £30. We also receive requests from many returning families for larger clothing as their children outgrow their Warrior Packs. It is our commitment to these children to meet these needs wherever possible as part of our core charitable objectives.

We know from the many messages we receive on a weekly basis what these packs mean to families and children growing up with cystic fibrosis, and we aim to respond to every request positively so that every child born with this disease can be included in the community.

Research Funding

Partnership between the School of Sport, Health and Exercise Science (University of Portsmouth) and the CF Warriors charity

This partnership is an initial three-year collaborative programme of research and dissemination of knowledge and education between the **School of Sport, Health and Exercise Science at the University of**

Portsmouth and the CF Warriors charity.

Central to this partnership is the promotion of the benefits of physical activity, exercise and good nutrition for people with cystic fibrosis. This involves conducting research studies to answer important questions raised by people with cystic fibrosis to help them engage in safe and effective lifelong exercise, as well as translating and publicising our collaborative research findings and other key educational sessions to people with cystic fibrosis through the charity network.

The 3 years, full-time, fully funded PhD studentship is being supervised by Dr Zoe Saynor, a world leading expert in exercise and cystic fibrosis, and an active member of the European Cystic Fibrosis Society exercise working group, alongside Dr Jo Corbett and Dr Anthony Shepherd.

Additional clinical and research input will also come from clinical colleagues and an ongoing collaborative with the adult and paediatric cystic fibrosis services at the University Hospital Southampton NHS Foundation Trust.

The title of the PhD is:

Exercise and nutrition for people with cystic fibrosis in the modulator era.

The successful candidate will join the [Physical Activity, Health and Rehabilitation Thematic Research Group](#), led by Dr Zoe Saynor, whilst also working closely with colleagues in the [Extreme Environments Thematic Research Group](#). This position also involves working closely with clinical colleagues (clinicians and physiotherapists) within the respiratory and paediatric departments at the University Hospital Southampton NHS Foundation Trust. The primary research environments are the [exercise laboratories](#) at the University of Portsmouth. The successful candidate will be working in a team with her supervisors and clinical staff and will be fully immersed in running clinical trials and the analyses of data.

They are expected to conduct research that has been informed by people with cystic fibrosis and aims to benefit people with cystic fibrosis.

Specifically, the research undertaken aims to further our understanding on the topics of exercise and nutrition for people with cystic fibrosis as we transition into the modulator era, building on previous work conducted by the supervisory team.

This PhD studentship is an exciting opportunity in partnership with the Charity, and the student will also be working closely with the charity to disseminate research findings to people with cystic fibrosis and their families.

As well as conducting research, Dr Zoe Saynor and the PhD student will collaborate closely with the charity and will be available to deliver monthly Q&A sessions through the CF Warriors platform. Both will also be available to deliver educational sessions. Josh Llewellyn-Jones has agreed to provide a talk at the University of Portsmouth free of charge once a year as part of the program. Dr Zoe Saynor will be an advocate for the charity and available when needed for talks / Q&As free of charge.

PhD Programme of Research to commence in October 2021:

The schedule of research is as follows:

- Study 1 Evaluate the current hydration / salt requirement for people
- Study 2 Evaluate the experiences of people with CF who are now on regarding their sweat responses, hydration and nutrition req evaluate current salt tablet use and nutritional supplement u
- Study 3 Laboratory study: Explore the thermo-physiological response dehydration in people with cystic fibrosis during exercise in r conditions and exercise in the heat compared to healthy peo changed on modulators
- Study 4 Evaluate the knowledge regarding diet and exercise in people
- Study 5 Assess the physical activity, glycaemic control and body comp children and adults with cystic fibrosis
- Study 6 Laboratory study: Explore the effects of an alternative low-su supplement versus currently prescribed supplements for ped fibrosis on glycaemic control, fat oxidation at rest and during vascular health

The initial grant of £25,200 was made this year, to be followed by a further two payments of £26,400 in October 2022 and £27,600 in October 2023.

Section E

Financial review

Brief statement of the charity's policy on reserves

Cash reserves at 31 March 2021 were £35,858 in unrestricted funds

The initial research funding grant of £25,200 was made this year, to be followed by a further two payments of £26,400 in October 2022 and £27,600 in October 2023. In order to continue our Warrior Pack Program alongside this research funding, it is necessary to hold at least £30,000 to cover the running costs of the charity.

Details of any funds materially in deficit

Not applicable

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


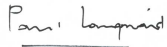
Other optional information

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)	Josh Llewellyn-Jones OBE	Paul Langmaid CBE
Position (eg Secretary, Chair, etc)	Trustee	Trustee
Date	25/1/2022	



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name CF Warriors	No (if any) 1178063
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CC16a

Receipts and payments accounts

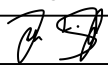
For the period from	Period start date 01/04/2020	To	Period end date 31/03/2021
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Section A Receipts and payments

	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					
Donations	28,959	-	-	28,959	97,002
Event sponsorship and ticket sales	-	-	-	-	9,762
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	28,959	-	-	28,959	106,763
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	28,959	-	-	28,959	106,763
A3 Payments					
Grants to fund research	25,200	-	-	25,200	-
"CF Warrior" packs distributed free of charge	17,750	-	-	17,750	13,963
Employee costs	22,268	-	-	22,268	8,746
Office costs and fundraising expenses	4,632	-	-	4,632	22,577
Social media expenses	3,010	-	-	3,010	1,750
Legal and professional fees	1,873	-	-	1,873	1,128
Communication and IT expenses	1,847	-	-	1,847	822
Bank and payment processing fees	883	-	-	883	1,010
Insurance	318	-	-	318	-
Donations	150	-	-	150	8,200
	-	-	-	-	-
	-	-	-	-	-
Sub total	77,931	-	-	77,931	58,196
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	77,931	-	-	77,931	58,196
Net of receipts/(payments)	- 48,972	-	-	- 48,972	48,567
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	84,831	-	-	84,831	36,264
Cash funds this year end	35,858	-	-	35,858	84,831

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	Cash at bank	36,500	-	-
	Loan balance	-	-	-
		-	-	-
	Total cash funds	35,858	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
B2 Other monetary assets	Details	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B4 Assets retained for the charity's own use	Details	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B5 Liabilities	Details	-	-	-
	Other taxation and social security	Unrestricted	639	-
		-	-	-
		-	-	-
		-	-	-

Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval
		Josh Llewellyn-Jones	25/1/2022
	<u>Paul Langmaid</u>	Paul Langmaid	25/1/2022



Section A

Independent Examiner's Report

Report to the trustees/
members of

CF Warriors

On accounts for the year
ended

31 March 2021

Charity no
(if any)

1178063

Set out on pages

The Trustee's Report and Accounts set out on pages 1 to 13 of the attached report

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 31 March 2021

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.

Signed:

Date:

25 January 2022

Name:

Stephen Thomas

Relevant professional
qualification(s) or body
(if any):

ACA

Address:

Fairoaks, 1 Pentre-poeth Road, Bassaleg, NP10 8LN