



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

 UNIVERSITY OF PORTSMOUTH

 WARRIORS


Josh Llewellyn-Jones OBE

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 | - Dawn Llewellyn-Jones |
| - Stuart Clarke | - Adrian Llewellyn-Jones |
| - Paul Madley | - 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 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 | |

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
- The Gibson Family
- Elaine Milne
- The MDRT Foundation
- Lumen Financial
- Jemma & Tricia Morris - Denval 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:

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



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name
CF Warriors

No (if any)
1178063

Receipts and payments accounts

CC16a


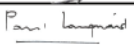
For the period from	Period start date	To	Period end date
	01/04/2021		31/03/2022

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	-	-
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets	Details			
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
	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	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.

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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 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

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
- Dover Leisure Centre
- Elaine Milne
- The MDRT Foundation
- Lumen Financial
- Jemma & Tricia Morris - Denval 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.