



# Caudwell LymeCo Annual Report & Accounts

A Charitable Incorporated Organisation

**2020**

Our key developments and financial figures  
from 1st January 2020 to 31 December 2020

CHARITY REGISTRATION NUMBER: 1169342

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## Reference and Administration Details

**Charity Name:** Caudwell LymeCo Charity  
**Other names charity is known by:** Caudwell Lyme Disease  
**Registered charity number:** 1169342

**Charity's Principal Address:** Caudwell LymeCo  
Broughton Hall  
Broughton  
Nr. Eccleshall  
ST21 6NS

### Trustees who managed the charity:

- John Caudwell (Chair)
- Rebekah Caudwell (resigned September 2020)
- Michael Fenton
- Joanna Seabright (appointed January 2020)
- Emma Sandbach (appointed August 2020)

Charity Manager: Rosie Milsom

### Structure, Governance and Management

Caudwell LymeCo is a Charitable Incorporated Organisation (CIO), and is governed by a foundation model constitution document.

The Charity is governed by a Board of Trustees which throughout the year comprised a chair (John Caudwell) and three further trustees. The charity recruited additional trustees during this reporting period, and saw the resignation of one.

All trustees give their time voluntarily and receive no remuneration or other benefits. The main benefactor of the Charity, John Caudwell, covers the core operational and administrative costs of the organisation. Therefore, all further fundraising income can be put directly towards accomplishing the objectives of the Charity.

### Our Charity's Aims

Our vision is for every Lyme disease patient in the UK to be treated and completely cured on the NHS.

Our mission is to fund research that finds a truly reliable diagnostic test and treatment for Lyme disease that cures every person.

### Objectives and Activities

The objectives of the Charity are:

*1. to promote and protect the physical and emotional health of sufferers of Lyme disease and associated diseases and medical conditions in the UK and beyond through the provision of support, education and practical advice;*

The Charity achieves this through providing evidence-based information on its website, [www.caudwelllyme.com](http://www.caudwelllyme.com) free of charge to the public, and through our patient information service, offering advice on diagnosis and treatment based on the NICE Guideline for Lyme disease.

*2. to advance the education of the general public throughout the UK and beyond in all areas relating to Lyme disease and associated diseases in particular but not exclusively by raising awareness, providing information and educational materials and disseminating research, for the benefit of all Lyme disease sufferers, both diagnosed and currently undiagnosed;*

The Charity achieves this through disseminating awareness-raising material to targeted areas, media appearances to reach the public and through the downloadable teaching materials on its website, with a focus on Lyme disease prevention. The organisation also delivers free awareness talks to community groups, distributes leaflet information and resources within communities, and attends events and conferences to help educate the public and health professionals.

*3. to promote, sustain and increase individual and collective knowledge and understanding on the subject of Lyme disease and associated diseases and medical conditions amongst medical professionals, healthcare providers and the scientific community in the UK and beyond, by collating and disseminating research, by carrying out research and by making grants to fund such research as the trustees see fit from time to time for the public benefit, and to publish the useful results of that research, and through such other means as the trustees see fit.*

The charity achieves this through its medical research programme and grant funding.

In planning our activities for the year we kept in mind the Charity Commission's guidance on public benefit at our trustee meeting.

### **Fundraising Activity Statement**

In 2020 the charity raised its funding through a mixture of individual giving, fundraising campaigns, community fundraising, trade income and corporate giving. We manage our own fundraising campaigns, memberships, donations and partnerships in house, and do not use external suppliers or third party commercial partners.

The public are invited to make one-off or regular donations via our website, and were encouraged to donate via The Big Give platform during our Christmas Campaign.

Members of the public and volunteers have chosen to raise money on our behalf through the completion of challenges, events and collections. They are given the necessary support and materials to do this, including a certificate of authorisation if required.

Though we are not registered with a body such as the Fundraising Regulator, we have built our practices and policies to ensure that we comply with the Code of Fundraising Practice, particularly where fundraising is carried out by us or by volunteers. We have not been subject to any investigations, and we received no complaints about our fundraising.

All fundraising activities are carried out in accordance with GDPR regulations, adhering to our Safeguarding Policy, Donor Policy, and all other relevant guidelines to ensure vulnerable people are protected and no unreasonable methods are used to gain donations or data.



## Trustees' Report - Achievements & Highlights from 2020

For many charities, 2020 was a difficult year. The coronavirus pandemic brought with it many challenges. For us, it brought our talks with the government on co-funding research to a standstill.

But rather than stay still, we pivoted our strategy to strike out on our own and get things moving. This saw us develop our own research strategy, recruit a scientific advisory committee, and create our Innovation Fund - the first research programme of its kind by a Lyme charity in the UK.

Because of the support of our generous donors and amazing fundraisers, our fundraised income remained steady in 2020, despite the social restrictions and event cancellations.

As well as working towards this life-changing research, our charity was busy campaigning to raise awareness of the disease in 2020. When lockdown hit, we moved our free awareness talks online. This proved to be a successful move, as by the end of the year we'd managed to reach over 600 people.

We've also continued to provide information and advice to patients on diagnosis and treatment, based on the NICE Guideline, as the the only UK charity providing and advertising this specific helpdesk service.







Our particular thanks go to our donors, LifeLyme members, fundraisers, and business such as *Kidunk Clothing*, *SimplyV* and *CBDShopy* for their support. A shoutout also to *Prima Solutions*, *The Coyle Group* and the *Conrad Family Office* who supported during our successful 2020 Big Give campaign.

We are so excited to begin funding research in 2021, and making great strides towards improving care for Lyme disease patients in the UK and beyond. Until then, read on for our annual report of 2020.

**Rosie Milsom**

Caudwell LymeCo Charity Manager

## Our 2020 key achievements

 	<b>We give advice, information and support to over 250 patient a year via our helpdesk service.</b>	 
<b>We created and launched the first Lyme disease research fund of its kind by a charity in the UK.</b>	 	<b>We delivered free online awareness talks that reached over 600 people from outdoors organisations and community groups.</b>

## January 2020

The year 2020 began with the news that pop star, Justin Bieber had Lyme disease. This caused quite a bit of media interest, and we took the opportunity to chat to a local BBC radio station about Lyme in the UK.

We also delivered our first free awareness talk of the year to *The Outrigger Club* (a rowing group) in Newcastle Under Lyme, and welcomed a new Trustee! Jo Seabright (left image) is a marketing professional who was diagnosed with Lyme in 2018 and is keen to raise awareness.



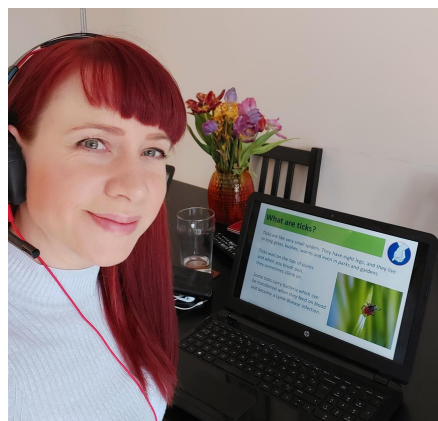
## February 2020

In February, Rosie Milsom was interviewed for *Pharmafield*, a healthcare magazine for professionals working with the pharmaceutical industry. She spoke about Lyme disease, the need for effective treatments, and the role that the industry can play in supporting research and patients.

We also held our first virtual fundraising quiz! An activity that would become popular for many over the coming months.....

## March 2020

As the coronavirus pandemic spread throughout the UK and we went into lockdown, the charity had to adapt some of its services.



Many Lyme sufferers were concerned about whether their health issues meant they were more at risk. We stayed open throughout lockdown to continue to offer support to the public, and to continue raising awareness.

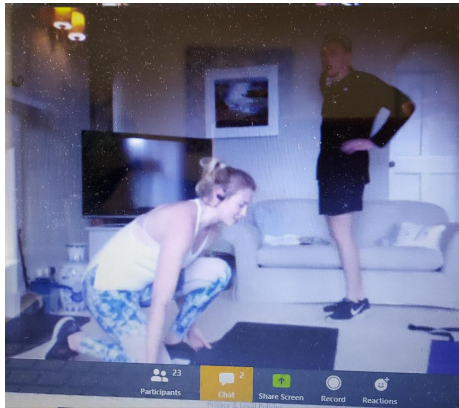
We converted our free awareness talks so they could be delivered online, and began reaching out to organisations who might benefit from them, especially at this time when staff were being pulled of their usual jobs.

During this time of uncertainty, we were truly grateful for our LifeLyme members and other donors who kept supporting us through this difficult time, and continue to do so now.

## April 2020

April saw an increased demand for our free online talks, as we delivered to *Staffordshire & Surrey Wildlife Trusts*, *The Woodland Trust* and *Forestry England*.

The charity also took part in the 2.6 Challenge, with some amazing fundraisers helping to raise over £2,000 towards Lyme disease research.



Among them, Milly Flynn ran a 26 minute online fitness class, and our Trustee Jo Seabright, ran 2.6 miles every day for 7 days! Rosie hosted a Facebook Live gig for family and friends.

We're so grateful for the support of the fundraisers and donors, as they helped to replace some of the funding we were losing due to the cancellation of other sporting challenges and events.

## May 2020

May is Lyme Awareness Month and despite the continuation of social distancing and reduced opportunity of face-to-face work, we continued with our plans to spread the word about Lyme.



Activities included blogs on nutrition for Lyme disease, tips from a counsellor on how to manage mental health when chronically ill, a Facebook Live quiz and a Q&A with tick-borne disease researcher, John Tulloch of *Liverpool School of Tropical Medicine*.

Our awareness raising posts on social media reached over 25,000 people.

We were also supported by young singer, Toby, who released a charity single called *Never Going To Love You* about his battle with Lyme. Pre-sale profits came to Caudwell LymeCo and Lyme Disease UK.

## June 2020

In June, Caudwell LymeCo volunteer, Justine Shuttleworth appeared on *BBC Radio 4's One on One* programme to talk about her battle with Lyme, which was a very well received interview and a great platform from which to share her story.

We also sourced the opportunity to write an article for *Singletrack Magazine*, a popular publication for mountain bike riders.

We got a great response to the article and hope it helps to keep some of the bike enthusiasts safe.



## July 2020

July was a busy and exciting month for the charity.

On the 1st we launched **Walk, Ride or Climb for Lyme**, a virtual event created in response to the negative impact that coronavirus has had on our fundraising. From 1 Jul to 30 Sep we encouraged our supporters to take on a challenge of their choosing to help raise money for Lyme disease research.



We also launched an exciting new initiative with our corporate partner, kids outdoor clothing company *Kidunk*, aimed at raising awareness and educating young children about Lyme disease. Our free downloadable resource has been endorsed by forest school practitioners and was rolled out to summer and nursery schools across the UK.

We delivered free online awareness talks to *Bedfordshire*, *Cambridgeshire* and *Northamptonshire Wildlife Trust*, and *Jogging Pals*, a large running group in Cumbria.

Rosie was a guest on popular station, *Lake District Radio*, chatting about ticks and Lyme disease and helping to raise awareness in a part of the UK that often sees many cases.

And we contributed to an article for *Trail Running Magazine*, helping to spread the word with those runners who head out into the countryside.



## August 2020

August saw us partner up with *SimplyV* to promote tick bite safety and removal with their Tick Twister tools. Both organisations shared awareness raising posts on their social media, and SimplyV donated 10% of Tick Twister sales from the month of August to our charity.

Rosie appeared as a guest on BBC York Radio to talk about Lyme disease, and we recruited a new Trustees, Emma Sandbach. She brings with her experience in research and public health.

It was also during this month that Chris Sergeant took part in Walk, Ride or Climb for Lyme, fundraising for us for the second year in a row. He took on an epic 300km round trip from Richmond Park to the New Forest and back in memory of his friend Darren, raising over £2,200.

The 'North Coast Numptys' also completed the North Coast 500 mile route in Scotland, raising an amazing £12,000!



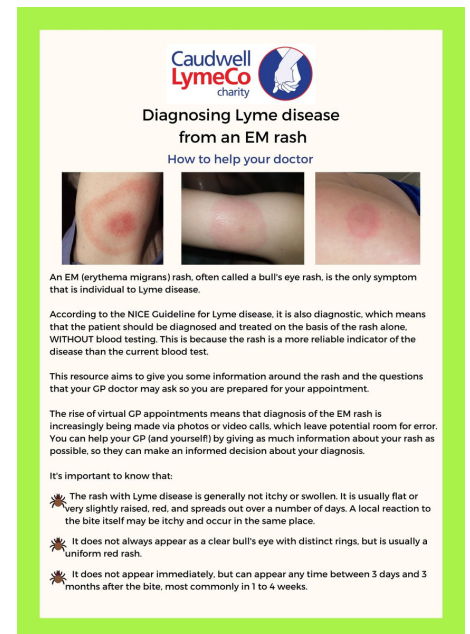
## September 2020

In September, we responded to an issue brought about from the rise in virtual GP appointments during the pandemic.

Many who developed a skin condition or rash were being diagnosed from a photo or video of their mark. When it comes to Lyme disease, the EM (erythema migrans) or bull's eye rash has some distinct characteristics which are not easy to ascertain from a photo.

We were hearing of patients with a genuine EM rash being told they have a simple insect bite and therefore not getting treatment. Or some patients are being diagnosed with Lyme when they have just a mosquito or horsefly bite.

To help with this issue and enable patients to make the most out of their GP appointment, we created a FREE downloadable resource.



We also saw our *Walk, Ride or Climb for Lyme* campaign come to an end with some more great fundraisers. Together they raised over £15,000 which is just amazing!

This included 3 year old Mabel taking on a hike and raising £200, and the Dutfield family taking on all three activities in support of the campaign via our partner *Kidunk Clothing*.

During September, Millie Bromley-Davenport also ran a marathon and raised over £1,100 for our charity. We are so grateful for all of their support.

## October 2020

In October we made the exciting announcement that we had launched our own Lyme disease research programme, which would begin funding projects in 2021.

Up until that point, we'd be in talks with the government to co-fund a project into Lyme disease testing. But then the pandemic hit and talks understandably slowed. Rather than delay life-changing research for any longer than necessary, we made plans to strike out on our own and get things moving.

We created a research strategy and recruited a fantastic scientific advisory committee to help us make informed funding decisions on projects that will have the biggest impact for patients. We also registering as a member of the Association of Medical Research Charities (AMRC) – a special hallmark accreditation for quality research. We look forward with excitement to funding projects in the first programme of its kind by a charity in the UK.



## November 2020

During this month we watched with joy and gratitude, the unfolding Monologues for Lyme campaign run by international voice coach, Rachel Preece.

Rachel caught Lyme after being bitten by a tick whilst pruning a tree in her mother's back garden in Herefordshire. She had struggled to get the correct diagnosis and treatment from her doctor and sought help from Caudwell LymeCo.

To show her gratitude for our support, she enlisted her actor and performer friends to record monologues and songs which she shared on social media throughout the month, encouraging donations. She raised over £1,200! And raised a lot of awareness too.





## December 2020

December saw us running our second successful Big Give Challenge campaign, where generous donors helped us raise over £7,000.

We also delivered a number of awareness talks to Wildlife Trusts across the country.

And we had our own charity bake off happening, as Joanna Upward and Harriet Wildman raised funds for the charity by designing their very own "Lyme drizzle cake" recipe and running a competition online.

## Supporting patients

We are pleased and proud to offer an information and advice service to patients looking to navigate the NICE Guideline. We have provided support to well over 250 people during the last year.

Here is a quote from a couple of patients we've helped in the last 12 months:

*"I fell ill with awful flu like symptoms a couple of years ago. I was given 7 days of amoxicillin and felt fine for a few weeks, but then relapsed and felt very ill for the next 2 years. I was diagnosed with Chronic Fatigue Syndrome. However, I knew there was something else wrong. I rang my GP they agreed to test me for Lyme disease. The test came back in their words 'borderline positive'.*

*This led to a lot of confusion. I straight away contacted Rosie at Caudwell LymeCo for advice. She explained to me about the NICE Guideline and was great throughout all this, providing a listening ear and signposting me to the right information. I am incredibly grateful, as without her I might not have pushed the way I have to find out if I had Lyme disease."*

Edward, Lyme disease sufferer

*"Thanks so much for your help, I feel much more optimistic now. It's so refreshing to speak to someone who is knowledgeable and understands about the disease. And someone who just "gets it".*

*Now, because of having the confidence and information to speak to my GP, I have been referred to a neurologist who is looking into further treatment options. Your help really appreciated and I wouldn't have known what to do without your advice."*

Natalia, Lyme disease sufferer

## Our thanks go to

We are incredibly grateful for the support of our LifeLyme members, donors, fundraisers, Trustees, volunteers and partners, who make our work possible. Because of them, we begin research next year that will work towards improving NHS care for Lyme sufferers.

During a difficult year, our income stayed steady thanks to the dedication and support of these people.

See a list of these key supporters on the next page.

## LifeLyme Members

Thank you to those who gave monthly to the charity during 2020, who are listed below. They allowed us to rely on regular income at a very uncertain time for charities, and we are truly grateful.

- Graham Bagnall
- Joy Bray
- Sandra Clements
- Teresa Cook
- Robert Croydon
- Janet Cutts
- Dee Dadswell
- Tom Davey
- Alan Davidson
- Pat & Ron Etchells
- Michael Fenton
- Carina Gouveia Carreira
- Sarah Green
- Catherine Hancox
- Robert Hood-Wright
- Lee Marsden
- Andy Milsom
- Adrian Ratcliffe
- Desmond Scott
- Jo Seabright
- Kathleen Seaton-Stedham
- Vesna Stankic
- Jan Stevenson
- David Tyndall
- Sharron Wight
- Anonymous members

## Fundraisers

A big thank you to all of our fundraisers from 2020, who despite what was going on in the world, stood with us and raised an incredible amount of money.

Here are some of them below.



## Financial Review 2020

With the support of the major benefactor (Mr. Caudwell) meaning that the administrative, operational and payroll costs of the Charity are covered outright, every further pound that is donated is put directly towards accomplishing the objectives of the charity.

Thanks to the support and hardwork of the Trustees, Charity Manager and most importantly our incredible donors and fundraisers we were able to maintain income from donations at the same level as it was in 2019, in spite of the unprecedented events that we all faced in 2020.


The primary expenditure in the year aside from payroll has been to support the fundraising efforts of those who take part in sponsored events and challenges, and on marketing and promotion of the charity and its awareness activities.

### **Reserves Policy**

The Charity has no specific policy on reserves as the running costs of the Charity are covered by the main benefactor. Therefore all unspent donations which are not from the main benefactor are held in restricted funds and will be specifically used for the purposes of accomplishing the Charity's objectives, when the Trustees determine that such expenditure will have the greatest impact. £106,488 of restricted funds is held at year end and will be carried forward for this purpose.

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

**Signed on behalf of the Charity Trustees:**

**Signature:** 

**Full Name:** Michael Fenton

**Position:** Trustee

**Date:** 25/10/2021

**Independent Examiner's Report** to the trustees/ members of Caudwell LymeCo Charity, number 1169342. On Accounts for the period ended 31<sup>st</sup> December 2020, set out on page 14.

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts in accordance with the Charities Act 2011 ("the Act").

The charity's trustees consider that an audit is not required for this year under section 144 of the Act and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the Charities Act,
- to follow the applicable Directions given by the Charity Commission (under section 145(5)(b) of the Act, and
- to state whether particular matters have come to my attention.

Basis of independent examiner's statement

My examination was carried out in accordance with general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the statement below

Independent examiner's statement

In connection with my examination, no material matters have come to my attention 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:   x Oliver Stidwell  

Date:   26/10/2021  

Name:   Oliver Stidwell  

Relevant Professional Qualifications:   ACA  

Address:   15 Herbert James Close, B66 4TF

**Receipts and Payments Accounts**

For the Period from 01/01/2020 to 31/12/2020

Figures are disclosed to the nearest £.

**Statement of Receipts and Payments for the period:**

	Unrestricted Funds 2020	Restricted Funds 2020	Total Funds 2020	Last Year 2019
	£	£	£	£
<b>Receipts</b>				
Unrestricted Donations	55,026	-	55,026	57,507
Restricted Donations	-	33,560	33,560	34,980
Interest Income	-	154	154	287
<b>Total Receipts</b>	<b>55,026</b>	<b>33,714</b>	<b>88,739</b>	<b>92,774</b>
<b>Payments</b>				
	£	£	£	£
Payroll Costs	(50,524)	-	(50,524)	(67,720)
Marketing and Promotional Materials	-	(470)	(470)	(454)
Costs of Raising Funds	-	(678)	(678)	(1,130)
Awareness Raising Activities		(423)	(423)	(475)
Expenses	(153)	-	(153)	(772)
<b>Total Payments</b>	<b>(50,677)</b>	<b>(1,570)</b>	<b>(52,247)</b>	<b>(70,552)</b>
Net of receipts/(payments)	4,349	32,144	36,493	22,222
Transfers between funds	-	-	-	-
Cash funds last year end	339	74,344	74,684	52,461
<b>Cash Funds This Year End</b>	<b>4,688</b>	<b>106,488</b>	<b>111,176</b>	<b>74,684</b>

**Statement of Assets and Liabilities at the end of the period:**

	Unrestricted Funds 2020	Restricted Funds 2020	Total Funds 2020	Last Year 2019
	£	£	£	£
<b>Cash funds</b>				
Cash held at bank:	4,688	106,488	111,176	74,684
<b>Liabilities</b>				
PAYE/NIC/Pension liability relating to December 2020 payroll	(1,412)	-	(1,412)	(788)

Note that this liability was funded out of unrestricted funds post the end of the financial period.