

**Report of the Trustees and
Unaudited Financial Statements for the Year Ended 31 December 2020
for
CDLS FOUNDATION UK & IRELAND**

Knox Cropper LLP
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**Report of the Trustees
for the Year Ended 31 December 2020**

The trustees present their report with the financial statements of the charity for the year ended 31 December 2020. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

Its Mission:- "The CdLS Foundation UK & Ireland is a family support organisation which exists to ensure early and accurate diagnosis of CdLS throughout the world, promoting research, and enabling individuals, families, friends and professionals make informed decisions and plan for the affected person's present and future."

Main activities

To achieve its aims and objectives, the CdLS Foundation carries out the following activities: Usually, the CdLS Foundation holds twice yearly family conferences, a telephone helpline, publication of treatments and guidance for manifestations of the syndrome, information about the condition published in a twice yearly magazine, website and social media pages. Due to the Covid-19 pandemic, family conferences were replaced by virtual online events for 2020.

Public benefit

The public benefit of our activities falls into 2 areas. For families affected by CdLS, the benefit of our activities is that they have the best and most up to date relevant information in making decisions about the person they care for. For the wider public, the benefit of our activities is an awareness of the condition so that diagnosis is easier and minimising the drain on healthcare and other resources through informed care for affected people. In shaping our objectives and planning our activities, the trustees have considered the Charity Commission's guidance on public benefit, Guides PB1, PB2 and PB3.

**Report of the Trustees
for the Year Ended 31 December 2020**

ACHIEVEMENT AND PERFORMANCE

This report is intended to give an overview of our activities during 2020 and an insight into the work of the Trustees:

Our usual twice yearly conference activities were severely curtailed by the global pandemic in 2020. As usual, we had planned our locations for the year in advance and had dates in the diary for both Spring and Autumn events. In particular, dates blocked out with our professionals who would likely be able to attend. We had a venue ready to put on the Spring conference in Basingstoke. We kept a reservation after having to at least postpone the event, in the hope things would be viable again in the Autumn. Sadly, this was not to be the case. Neither conference could go ahead.

As well as restrictions on hotels and the varying lockdown situations around the UK and Ireland, we felt safety of all of our families and especially our CdLS people, was the main consideration.

However, the awareness raising about CdLS and issues around the syndrome took on greater significance with greater effort needed to reach out across the UK and Ireland to ensure we connect with families old and new, in the best possible ways in a lockdown situation.

There was the need to advise continually on issues around Covid and CdLS. As well as getting the best advice we could from around the world about how Covid might affect people with CdLS, we had to source and disseminate official advice around the ever changing issues of shielding, schooling and all of the safety measures put in place.

Restrictions, social distancing, disruption to routine, school closures, all had a significant impact on our CdLS people. As well as often seen issues around social anxiety and aversion to change of routine in CdLS, explaining to people with any degree of intellectual disability about safety issues such as social distancing or why their school is closed, was always going to be challenging.

This is where our behavioural advisors helped us hugely with tailored advice on mental health issues and dealing with our CdLS people getting "cabin fever."

The challenge was to get all of this information to our families as effectively as possible. As well as the magazine, our website and office helpline, this is where social media came into its own. As soon as information was updated or new advice received, we could get it out to the majority of our families immediately.

As well as advice specific to the pandemic, we embarked upon a campaign presenting key facts about CdLS as a lead up to International Awareness Day. New families getting a diagnosis, when trying to research CdLS, found information that was incorrect, so it was vital that we were able to reach out to them with accurate and up to date information.

There was also some interest in the possibility of gene therapy for CdLS. We asked our experts globally to give us a statement on the state of play with genetic research into CdLS and the feasibility of a viable gene therapy, which was then disseminated to families.

The one event we could do, was to ensure that our online, virtual activities around International Awareness Day made an even bigger splash than usual. We are immensely grateful to families, trustees and regional volunteers who all contributed to the day.

All activity took place on social media, Facebook in particular, where we could schedule a series of videos, key facts about CdLS and share activities from around the world. We finished off the day with a virtual pub quiz, similar to what we would do at an in-person conference.

**Report of the Trustees
for the Year Ended 31 December 2020**

Some of our families conceived an idea for a collaborative awareness video, which we were delighted to adopt and promote. The idea was to take a 3D cardboard version of our Cube logo, receive it from one side and pass it to the other side. Edited together, the cube was being passed from person to person in many different locations around the world. Families from Australia joined us. We were given some original music and a professional video producer put the whole montage together for us with a running series of captions giving key information about CdLS. This was a very successful awareness and fund raising tool.

Our colleagues in Italy had a similar idea and shared it with many of us around the world in an international awareness video that was also fantastic.

In all, the efforts for Awareness Day generated around £14,000 of income with all the generous donations received.

On a sadder note, we said goodbye to a key figure in the research and development of knowledge and understanding of CdLS. Professor Laird Jackson from the USA passed away late in 2019. We paid tribute in our first magazine of the year. He appeared at many of our early conferences and fostered a generation of scientists and medical professionals to take an interest in CdLS. His contribution was immeasurable.

Our sister organisation in the USA were due to have their 2-yearly national conference in 2020. Because of Covid, they decided on a virtual event and were kind enough to open it up to everyone around the world. It was a very successful online event with live chat, keynote presentations and live Q&A sessions and some live music entertainment.

This set up many of the CdLS groups around the world to do something similar. The UK & Ireland Foundation were no exception. We staged a one day virtual conference in place of our regular Autumn event. This too was very successful and available to families around the world. Sadly we could not offer any translation for non English speakers but it was very well received by those that did attend.

We had nearly 120 registrations for the event, which gave that number of households (and therefore many more people) a chance to watch online. Keynote addresses were prerecorded and specifically tailored to questions our families wanted answering, which we had canvassed for in advance. It gave the presentations more focus. Each was followed by a live Q&A session. Introductions and an interval were prerecorded with information about the Foundation and what we do. The whole event was available to watch on catch up for all registered attendees after the day. We were able to continue registering people after the event, which stayed online for 3 months after the day.

We could not hold an AGM in person and felt that a virtual one would detract from what the families really needed in terms of an online virtual presence of the Foundation. Our constitution was amended in line with the Charity Commission guidance to allow for this.

We did have one in person trustees board meeting in January, before the pandemic took hold. At the meeting we planned for the year, which of course had to be changed, and set a budget of £60,000 as likely expenditure for 2020. This included an average of £4,000 per year for the next three years to fund the next behavioural research PhD, proposed by Dr Jo Moss. Sadly this research was put on hold due to the pandemic.

In the event, reduced expenditure meant that we actually made a profit. Fundraising was up on 2019, yielding an income of £58,000 versus expenditure of £33,000 approx. This is very good news for the Foundation, meaning we maintain our policy of having sufficient funding in the bank for 2 years' worth of normal activities.

FINANCIAL REVIEW

Investment policy and objectives

The charity's investment is low risk and is held on a high interest account with Scottish Widows Bank.

Reserves policy

In the first instance The Foundation's aim is to hold two year's operating budget in reserve. Ideally it will grow reserves in order to hold sufficient capital to generate funds to cover the annual operating costs.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust and constitutes an unincorporated charity.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number
1054033

Principal address
PO Box 8368
Ripley
Derbyshire
DE5 4DA

Trustees

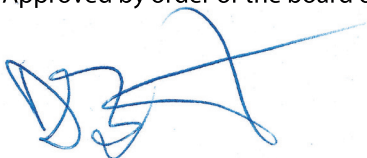
D Axtell (Chairman)
A Conlon (Treasurer)
Mrs C McCarney (Trustee)
Ms F Kett (Trustee)
R Saunders (Trustee)
Mrs S Peaford Smith (Trustee)
Mrs G Penney (Hon. Secretary)
C Blockley (Vice Chairman)
J Young (Trustee)

Independent Examiner
Knox Cropper LLP
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EVENTS SINCE THE END OF THE YEAR

Information relating to events since the end of the year is given in the notes to the financial statements.

Approved by order of the board of trustees on 11 June 2021 and signed on its behalf by:



D Axtell (Chairman) - Trustee

Independent examiner's report to the trustees of CdLS Foundation UK & Ireland

I report to the charity trustees on my examination of the accounts of CdLS Foundation UK & Ireland (the Trust) for the year ended 31 December 2020.

Responsibilities and basis of report

As the charity trustees of the Trust 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 Act and in carrying out my examination I have followed all 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 giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do 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.

Neil Wilkinson
FCA
Knox Cropper LLP
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Hertfordshire
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Date:

CDLS FOUNDATION UK & IRELAND

**Statement of Financial Activities
for the Year Ended 31 December 2020**


		2020 Unrestricted fund £	2019 Total funds £
INCOME AND ENDOWMENTS FROM	Notes		
Donations and legacies		33,328	20,212
Charitable activities			
Education and awareness		955	1,350
Other trading activities	2	24,688	31,666
Investment income	3	1	9
Total		58,972	53,237
EXPENDITURE ON			
Raising funds		2,476	4,327
Charitable activities	4		
Education and awareness		31,336	45,799
Research		-	13,064
Total		33,812	63,190
NET INCOME/(EXPENDITURE)		25,160	(9,953)
RECONCILIATION OF FUNDS			
Total funds brought forward		104,666	114,619
TOTAL FUNDS CARRIED FORWARD		129,826	104,666

The notes form part of these financial statements

Balance Sheet
31 December 2020

		2020 Unrestricted fund £	2019 Total funds £
	Notes		
CURRENT ASSETS			
Cash at bank		131,535	106,326
CREDITORS			
Amounts falling due within one year	9	(1,709)	(1,660)
NET CURRENT ASSETS		<u>129,826</u>	<u>104,666</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		129,826	104,666
NET ASSETS		<u>129,826</u>	<u>104,666</u>
FUNDS	10		
Unrestricted funds		<u>129,826</u>	<u>104,666</u>
TOTAL FUNDS		<u>129,826</u>	<u>104,666</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 11 June 2021 and were signed on its behalf by:



D Axtell (Chairman) - Trustee

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

Financial reporting standard 102 - reduced disclosure exemptions

The charity has taken advantage of the following disclosure exemptions in preparing these financial statements, as permitted by FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland':

- the requirements of Section 7 Statement of Cash Flows.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Computer equipment - 25% on cost

Taxation

The charity is exempt from tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Notes to the Financial Statements - continued
for the Year Ended 31 December 2020**2. OTHER TRADING ACTIVITIES**

	2020	2019
	£	£
Fundraising events	24,688	31,666

3. INVESTMENT INCOME

	2020	2019
	£	£
Deposit account interest	1	9

4. CHARITABLE ACTIVITIES COSTS

	Direct Costs £	Support costs (see note 6) £	Totals £
Education and awareness	7,566	23,770	31,336

5. GRANTS PAYABLE

	2020	2019
	£	£
Research	-	13,064

The total grants paid to institutions during the year was as follows:

	2020	2019
	£	£
University of Birmingham	-	13,064

6. SUPPORT COSTS

	Management £	Finance £	Governance costs £	Totals £
Education and awareness	21,245	125	2,400	23,770

7. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2020 nor for the year ended 31 December 2019.

Trustees' expenses

	2020	2019
	£	£
Trustees' expenses	392	4,003

8. TANGIBLE FIXED ASSETS

	Computer equipment £
COST	
At 1 January 2020 and 31 December 2020	4,500
DEPRECIATION	
At 1 January 2020 and 31 December 2020	4,500
NET BOOK VALUE	
At 31 December 2020	-
At 31 December 2019	-

9. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2020	2019
	£	£
Other creditors	1,709	1,660

10. MOVEMENT IN FUNDS

	At 1.1.20 £	Net movement in funds £	At 31.12.20 £
Unrestricted funds			
General fund	104,666	25,160	129,826
TOTAL FUNDS	104,666	25,160	129,826

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	58,972	(33,812)	25,160
TOTAL FUNDS	58,972	(33,812)	25,160

10. MOVEMENT IN FUNDS - continued**Comparatives for movement in funds**

	At 1.1.19 £	Net movement in funds £	At 31.12.19 £
Unrestricted funds			
General fund	114,619	(9,953)	104,666
TOTAL FUNDS	<u>114,619</u>	<u>(9,953)</u>	<u>104,666</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	53,237	(63,190)	(9,953)
TOTAL FUNDS	<u>53,237</u>	<u>(63,190)</u>	<u>(9,953)</u>

A current year 12 months and prior year 12 months combined position is as follows:

	At 1.1.19 £	Net movement in funds £	At 31.12.20 £
Unrestricted funds			
General fund	114,619	15,207	129,826
TOTAL FUNDS	<u>114,619</u>	<u>15,207</u>	<u>129,826</u>

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	112,209	(97,002)	15,207
TOTAL FUNDS	<u>112,209</u>	<u>(97,002)</u>	<u>15,207</u>

11. RELATED PARTY DISCLOSURES

Mr Alan Peaford is a director of Aerocomm Ltd. During the year, the charity paid £3,366 (2019: £2,878) for editing and production to Aerocomm Limited.

Natalie Blockley, who is the wife of Charles Blockley, was paid £15,600 (2019: £15,600) for administration services, during the year.

12. POST BALANCE SHEET EVENTS

The Trustees have considered the risks and potential impacts of the recent Covid-19 pandemic, which occurred before the Balance Sheet date. As a consequence of the lockdown there has been a reduced level of expenditure on charitable activities. However there has been no impact on its income and its ability to continue as a going concern.