

CdLS Foundation UK & Ireland

England & Wales · Charity number 1054033

Details

Other names	CORNELIA DE LANGE SYNDROME FOUNDATION UK, CD L S FOUNDATION
Status	Registered
Legal form	Other
Registered	1996-03-25
Register	View on the Charity Commission register

Contact

Address C D L S Foundation
PO Box 8368
Ripley
DE5 4DA

Phone 01375376439

Email info@cdls.org.uk

Website www.cdls.org.uk

Activities

Objects: TO ENSURE EARLY AND ACCURATE DIAGNOSIS OF CDLS THROUGHOUT THE WORLD TO PROMOTE RESEARCH AND TO ENABLE FAMILIES FRIENDS AND PROFESSIONALS TO MAKE AN INFORMED DECISION AND PLAN FOR THE AFFECTED PERSON'S PRESENT AND FUTURE

Activities: Providing information about this rare syndrome to families and professionals. Links with other CDLS support groups around the world to give information in different languages, meetings & research.

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£49,256	£46,292	-	-
2023-12-31	£61,959	£63,874	-	-
2022-12-31	£51,735	£54,234	-	-
2021-12-31	£45,243	£33,220	-	-
2020-12-31	£58,972	£33,812	-	-

Trustees

Name	Role	Appointed
Bjorn Harris		2022-04-27
CHARLES BLOCKLEY		2017-10-29
DAVID AXTELL		2012-10-14
Dr Bethany Pang		2025-01-22
FAYE KETT		2012-10-14
Jack Young		2019-06-27
Kim Wildborne		2024-09-16
Ryan Saunders		2013-05-04
Sara Peaford-Smith		2016-05-01

CdLS Foundation UK & Ireland

England & Wales - Charity number 1054033

Accounts

**Report of the Trustees and
Unaudited Financial Statements for the Year Ended 31 December 2024
for
CDLS FOUNDATION UK & IRELAND**

Knox Cropper LLP
Chartered Accountants
153 -155 London Road
Hemel Hempstead
Hertfordshire
HP3 9SQ

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The trustees present their report with the financial statements of the charity for the year ended 31 December 2024. 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: 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.

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.

ACHIEVEMENT AND PERFORMANCE

This report is intended to give an overview of our activities during 2024 and an insight into the work of the Trustees:

Our intention to hold 2 conference weekends per year was compromised in 2024 due to the big rise in venue costs. Not least of which was the fact that the Autumn location had been set for Republic of Ireland as per our rotation plan. The price of suitable venues in Ireland proved to be extremely costly and made it too expensive to budget for two conference weekends in 2024. We did have an early summer event in place of a full Spring conference. In June of 2024, we were kindly offered a free venue for such a day meeting. The Circus Skills Centre in Birmingham was a well located venue, where we could hold a family meetup and our AGM. It was a great social gathering of families and trustees. Also in attendance were psychology researchers from the nearby University of Birmingham, there to tell us about research programmes in progress and recruit families for the ongoing sleep project and others. Our kids could play on some of the circus equipment available, under close supervision. In most cases, just swinging on hoops and silks. Some of the trustees tried out their acrobatic skills! We also held our AGM as previously mentioned.

For the Autumn, we were in Dublin, ROI. The meeting was very well attended from both the Republic and Northern Ireland. The impetus for these events is aiming much more towards providing solutions to families, in so far as that is possible. The presentations were all aimed at solutions to common problems. As well as the medical issues, we were pleased to welcome Chair of the World Federation Care Council, Bernadette Dalingwater, to talk about managing the impact of having a person with CdLS within the family unit.

We continue to have each year's activities planned well in advance so we can announce the next event at each conference or other gathering.

There was no World Conference in 2024, as they should run every 2 years and there had been the Spanish event in 2023. Although there should be one in 2025, the Federation has decided on missing out so that they can reset after events getting too close together due to the pandemic. The next event will be in Australia in 2027.

At the AGM in Birmingham, the Trustees Report as well as the accounts for 2024 were presented, voted upon and accepted. Trustee Faye Kett was re-elected. David Axtell was re-elected as Chair, Charles Blockley re-elected as Vice Chair, Bjorn Harris re-elected as Treasurer, Ginny Penney as Hon. Secretary. Sadly, we said goodbye to trustee Cath McCarney, who stepped down after many years of service. She was thanked for all she contributed to the running of the Foundation. Later in the year, we were pleased to elect our host for the Birmingham event, Kim Wildborne, who volunteered to join the board.

In setting a draft annual budget, the Trustees agreed a figure of £65,500 for 2024 as the amount needed to meet the Foundation objectives for the year. This is to cover paid staff, office space, conference costs, website hosting, magazine print and distribution, trustees' expenses and other administration costs. We have also allowed for another payment towards the research project of PhD student, Bethany Jones, who is researching connections between autism and anxiety in CdLS.

We renewed our Run for Charity subscription. Fundraising received a big boost by being named as Charity of the Year by a company called Oprema. A father of a little girl with CdLS, Chris Cooper works for them and lobbied to get us made their charity of choice for 2024. This brought in around £5,000 for which we were extremely thankful. Overall, we returned to a modest surplus of £2,964 in 2024, compare to a loss of £1,915 in 2023. This reflects the success of cost control measures implemented during the year. Full details of our accounts are included herewith.

Beth Jones' PhD research project concluded and the fruits of that research can now be disseminated. We can look forward to learning about what was uncovered in the coming year. There was in fact an underspend on the project and we will have some of the funds we donated given back to us in 2025. This is not reflected in the 2024 accounts.

International CdLS Awareness Day 2024 was successful. The reach across our social media platforms was pretty broad, with a lot of engagement from our audience. It was also a good focus for fundraising.

**Report of the Trustees
for the Year Ended 31 December 2024**

We followed through the plan to extend our merchandise range. While this was a fairly large area of expenditure, it also gave us a longer term way to raise funds and awareness. We also put some much needed impetus behind compiling the content needed to complete the new website development. Various sub committees were formed to populate each section of the site. We are pleased to report that they have met to discuss sourcing information needed after a plan for what content was needed was formulated and shared. We expect to complete and launch in 2025.

FINANCIAL REVIEW

Financial position

Total income for the year was £49,256 (2023: £61,959) of which donations amounted to £16,758 (2023: 43,434) and fundraising events £31,086 (2023: £16,282). Total expenditure for the year was £46,292 (2023: £63,874) of which £37,703 (2023: £61,513) related to charitable activities. This gave rise to net income of £2,964 (2023: net expenditure of £1,915) for the year. The reserves at the end of the year amounted to £140,399 (2023: £137,435).

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. The year-end reserve stood at £140,399 (up from £137,435) which keeps us over the 2 year current reserves policy

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)
Mrs C McCarney (Trustee) (resigned 28.6.24)
Ms F Kett (Trustee)
R Saunders (Trustee)
Mrs S Peaford Smith (Trustee)
Mrs G Penney (Hon. Secretary)
C Blockley (Vice Chariman)
J Young (Trustee)
B Harris (Trustee)
Ms K Boland (Trustee)
Ms K Wildborne Trustee (appointed 16.9.24)

Independent Examiner

Knox Cropper LLP
Chartered Accountants
153 -155 London Road
Hemel Hempstead
Hertfordshire
HP3 9SQ

Approved by order of the board of trustees on 24 March 2025 and signed on its behalf by:

A handwritten signature in blue ink, appearing to be 'D Axtell', written over a faint circular stamp.

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 2024.

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

Knox Cropper LLP
Chartered Accountants
153 -155 London Road
Hemel Hempstead
Hertfordshire
HP3 9SQ

Date:

Statement of Financial Activities
for the Year Ended 31 December 2024

	Notes	2024 Unrestricted fund £	2023 Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies		16,758	43,434
Charitable activities			
Education and awareness		60	1,330
Other trading activities	2	31,086	16,282
Investment income	3	1,352	913
Total		49,256	61,959
EXPENDITURE ON			
Raising funds		8,589	2,361
Charitable activities			
Education and awareness	4	37,703	61,513
Total		46,292	63,874
NET INCOME/(EXPENDITURE)		2,964	(1,915)
RECONCILIATION OF FUNDS			
Total funds brought forward		137,435	139,350
TOTAL FUNDS CARRIED FORWARD		140,399	137,435

The notes form part of these financial statements

Balance Sheet
31 December 2024

		2024 Unrestricted fund £	2023 Total funds £
CURRENT ASSETS			
Debtors	8	100	-
Cash at bank		142,495	144,651
		<u>142,595</u>	<u>144,651</u>
CREDITORS			
Amounts falling due within one year	9	(2,196)	(7,216)
		<u>140,399</u>	<u>137,435</u>
NET CURRENT ASSETS			
		<u>140,399</u>	<u>137,435</u>
TOTAL ASSETS LESS CURRENT LIABILITIES			
		<u>140,399</u>	<u>137,435</u>
NET ASSETS			
		<u>140,399</u>	<u>137,435</u>
FUNDS			
Unrestricted funds	10	<u>140,399</u>	<u>137,435</u>
TOTAL FUNDS			
		<u>140,399</u>	<u>137,435</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 24 March 2025 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 exemption 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.

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.

2. OTHER TRADING ACTIVITIES

	2024	2023
	£	£
Fundraising events	<u>31,086</u>	<u>16,282</u>

3. INVESTMENT INCOME

	2024	2023
	£	£
Deposit account interest	<u>1,352</u>	<u>913</u>

4. CHARITABLE ACTIVITIES COSTS

	Direct Costs £	Support costs (see note 5) £	Totals £
Education and awareness	<u>11,785</u>	<u>25,918</u>	<u>37,703</u>

5. SUPPORT COSTS

	Management £	Finance £	Governance costs £	Totals £
Education and awareness	<u>21,257</u>	<u>2,465</u>	<u>2,196</u>	<u>25,918</u>

6. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2024 nor for the year ended 31 December 2023.

Trustees' expenses

	2024	2023
	£	£
Trustees' expenses	<u>1,740</u>	<u>2,696</u>

7. TANGIBLE FIXED ASSETS

	Computer equipment £
COST	
At 1 January 2024 and 31 December 2024	<u>4,500</u>
DEPRECIATION	
At 1 January 2024 and 31 December 2024	<u>4,500</u>
NET BOOK VALUE	
At 31 December 2024	<u><u>-</u></u>
At 31 December 2023	<u><u>-</u></u>

8. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023
	£	£
Prepayments and accrued income	100	-

9. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023
	£	£
Trade creditors	-	5,116
Other creditors	2,196	2,100
	2,196	7,216

10. MOVEMENT IN FUNDS

	At 1.1.24	Net movement in funds	At 31.12.24
	£	£	£
Unrestricted funds			
General fund	137,435	2,964	140,399
TOTAL FUNDS	137,435	2,964	140,399

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

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
General fund	49,256	(46,292)	2,964
TOTAL FUNDS	49,256	(46,292)	2,964

Comparatives for movement in funds

	At 1.1.23	Net movement in funds	At 31.12.23
	£	£	£
Unrestricted funds			
General fund	139,350	(1,915)	137,435
TOTAL FUNDS	139,350	(1,915)	137,435

10. MOVEMENT IN FUNDS - continued

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	61,959	(63,874)	(1,915)
TOTAL FUNDS	<u>61,959</u>	<u>(63,874)</u>	<u>(1,915)</u>

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

	At 1.1.23 £	Net movement in funds £	At 31.12.24 £
Unrestricted funds			
General fund	139,350	1,049	140,399
TOTAL FUNDS	<u>139,350</u>	<u>1,049</u>	<u>140,399</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	111,215	(110,166)	1,049
TOTAL FUNDS	<u>111,215</u>	<u>(110,166)</u>	<u>1,049</u>

11. RELATED PARTY DISCLOSURES

Mr Alan Peaford is a director of Aerocomm Ltd. During the year, the charity paid £1,504 (2023: £3,148) for editing and production to Aerocomm Limited.

Natalie Blockley, who is the wife of Charles Blockley, was paid £16,800 (2023: £16,800) for administration services, during the year.

CdLS Foundation UK & Ireland

England & Wales - Charity number 1054033

Accounts

**Report of the Trustees and
Unaudited Financial Statements for the Year Ended 31 December 2023
for
CDLS FOUNDATION UK & IRELAND**

Knox Cropper LLP
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CDLS FOUNDATION UK & IRELAND

**Contents of the Financial Statements
for the Year Ended 31 December 2023**

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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: 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.

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.

ACHIEVEMENT AND PERFORMANCE

This report is intended to give an overview of our activities during 2023 and an insight into the work of the Trustees:

We managed to continue holding two in-person conferences throughout the year. The main problem was finding hotel venues whose prices had not been raised beyond affordability. The Spring conference was planned to be in Scotland. All of the major cities, which had to be preferred locations due to population densities and accessibility, only had very expensive conference hotels to offer. To save money, we took a decision to break with the preferred weekend format for the Spring event, and use a University facility to host the conference day. For the Autumn, we did manage to find a location that was more within our budget.

We aimed to have locations and dates planned a year in advance, but the long term rotation plan to cover all regions as frequently as possible was rationalised into counting Southeast and Southwest as one. We could still announce the next event at each conferences.

We continued the same format for conference keynote speakers with longer sessions for each speaker and fewer speakers. Less content over the day but Q&A sessions at the end of each address were longer and more interactive as an open forum with a moderator prompting questions and comments. Workshops in the afternoon were continued, as they offer more hands-on practical help and advice.

The first family weekend was held at the University of Strathclyde, Technology and Innovations Centre in Glasgow, April 2023. Despite the perceived demand for an event in Scotland, this was not very well attended but there were enough families present to make it thoroughly worthwhile. We did see some families who hadn't attended for a very long time as well as some new ones. The AGM was conducted before the lunchbreak. The downside of this venue was that we didn't have a dedicated space we could use for an evening social event. Budget hotels were sourced close to the conference venue and some families stayed at the same hotel as the trustees, so some social engagement was possible.

Our second conference, held in October 2023, was at the Holiday Inn, Eastleigh near Southampton. This was a very convenient location for getting to. A well attended weekend once again, with some new families. As well as the keynote talks around the core subjects, we presented an Anxiety workshop with strategies on how to minimise the impact of this. We also introduced a new member of the SCAT, physiotherapist Johann Delport. Evening entertainment was also very well attended.

The World Federation of CdLS Support Groups was back on track with World Conferences after the postponement of the 2021 event to 2022. It did mean, however, that the event had to be held very late in the year so as to be at least 12 months after the previous one. In attendance were professionals and volunteer/leaders from the USA, Brazil, UK, Germany, Netherlands, Denmark, Poland, France, Colombia, Australia and many homegrown experts from the hosts, Spain. Families were mostly from Spain and Latin America with a few from France. No UK families were in attendance. Part of the reason for a lack of attendees from the rest of Europe was the timing. The event was held in school term time for most of us, although there was a late decision to officially designate the conference as a medical event and thus justify taking kids out of school. This came too late for people to alter plans.

The UK was represented by Chair David Axtell and Medical Director Dr Peter Gillett. There was a variety of topics on the first conference day but the second day was all very detailed genetics. We did see talks by some experts who we hadn't seen at conferences before. The conference days were preceded by the usual full day meetings of the Scientific Advisory Council (SAC) and the Federation Council, the latter chaired by the UK & Ireland Foundation as well as for a combined session. The SAC discussed how the updates of the International Consensus Statement on Diagnosis and Management of CdLS were progressing. A change in Presidency of the SAC was planned with Dr Feliciano Ramos intending to handover to Dr Paul Mulder from the Netherlands. The Federation Council meeting took many initiatives forward from previous meetings, together with a planned overhaul of the CdLS World website. The Executive Committee elections confirmed the continuation of the UK & Ireland as Chair/President, with Vice President - Netherlands, Treasurer - Australia, Hon Sec. - Netherlands, Future Conference Host - Australia, New Member Liaison - Israel.

**Report of the Trustees
for the Year Ended 31 December 2023**

At the AGM in Glasgow, the Trustees Report as well as the accounts for 2022 were presented, voted upon and accepted. Trustee Charles Blockley was re-elected. David Axtell was re-elected as Chair, Charles Blockley re-elected as Vice Chair, Bjorn Harris re-elected as Treasurer, Ginny Penney as Hon. Secretary.

In setting a draft annual budget, the Trustees agreed a figure of £58,000 for 2023 as the amount needed to meet the Foundation objectives for the year. This is to cover paid staff, office space, conference costs, website hosting, magazine print and distribution, trustees' expenses and other administration costs. We have also allowed for payment towards the research project of a new PhD student, Bethany Jones, who is researching connections between autism and anxiety in CdLS. Conference costs would show a big increase with another World Conference expenses added. It was also expected that the magazine would have an additional edition in 2023.

To add to our fundraising strategy, we renewed our Run for Charity subscription. Other initiatives were discussed, such as sponsorship of activity rooms at conferences. Fundraising received a big boost with 2 large legacy donations, where the Foundation was named as a beneficiary in 2 people's wills. This was much needed income with 4 and 5 figure sums bequeathed to us. We were close to breakeven point, but with the research funding being slightly overbudget, we made a loss of £1,200 on the year.

Beth Jones' PhD research project continued and the fruits of that research got closer for the benefit of our families. We were pleased to welcome a new member of the SCAT. As mentioned, we welcomed Johann Delpert at our Autumn conference. Johann is an orthopaedic physiotherapist who works with children with varying disabilities.

International CdLS Awareness Day 2023 was successful. The reach across our social media platforms was pretty broad, with a lot of engagement from our audience. It was also good focus for fundraising

It was also time to look at promotional tools such as merchandise branded for CdLS. Some new ideas were discussed and will be developed for our events. We received a donation of Fidget Toys to include in branded Goodie Bags.

Report compiled by Chairman David Axtell

FINANCIAL REVIEW

Financial position

Total income for the year was £61,959 (2022: £51,735) of which donations amounted to £43,434 (2022: 22,572) and fundraising events £16,282 (2022: 27,560). Total expenditure for the year was £63,874 (2022: £54,234) of which £61,513 (2022: £50,365) related to charitable activities. This gave rise to net expenditure of £1,915 (2022: net expenditure £2,499) for the year. The reserves at the end of the year amounted to £137,435 (2022: £139,350).

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

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REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number

1054033

**Report of the Trustees
for the Year Ended 31 December 2023**

Principal address

PO Box 8368
Ripley
Derbyshire
DE5 4DA

Trustees

D Axtell (Chairman)
Mrs C McCarney (Trustee)
Ms F Kett (Trustee)
R Saunders (Trustee)
Mrs S Peaford Smith (Trustee)
Mrs G Penney (Hon. Secretary)
C Blockley (Vice Chariman)
J Young (Trustee)
B Harris (Trustee)
Ms K Boland (Trustee)

Independent Examiner

Knox Cropper LLP
Chartered Accountants
153 -155 London Road
Hemel Hempstead
Hertfordshire
HP3 9SQ

Approved by order of the board of trustees on 29 June 2024 and signed on its behalf by:



D Axtell (Chairman) - Trustee

**Independent Examiner's Report to the Trustees of
CdLS Foundation UK & Ireland**

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

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Responsibilities and basis of report

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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

Knox Cropper LLP
Chartered Accountants
153 -155 London Road
Hemel Hempstead
Hertfordshire
HP3 9SQ

29 June 2024

CDLS FOUNDATION UK & IRELAND

**Statement of Financial Activities
for the Year Ended 31 December 2023**

	Notes	2023 Unrestricted fund £	2022 Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies		43,434	22,572
Charitable activities			
Education and awareness		1,330	1,465
Other trading activities	2	16,282	27,560
Investment income	3	913	138
Total		61,959	51,735
EXPENDITURE ON			
Raising funds		2,361	3,869
Charitable activities			
Education and awareness	4	61,513	50,365
Total		63,874	54,234
NET INCOME/(EXPENDITURE)		(1,915)	(2,499)
RECONCILIATION OF FUNDS			
Total funds brought forward		139,350	141,849
TOTAL FUNDS CARRIED FORWARD		137,435	139,350


The notes form part of these financial statements

CDLS FOUNDATION UK & IRELAND

Balance Sheet
31 December 2023

		2023 Unrestricted fund £	2022 Total funds £
CURRENT ASSETS	Notes		
Cash at bank		144,651	141,342
CREDITORS			
Amounts falling due within one year	8	(7,216)	(1,992)
NET CURRENT ASSETS		<u>137,435</u>	<u>139,350</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>137,435</u>	<u>139,350</u>
NET ASSETS		<u>137,435</u>	<u>139,350</u>
FUNDS	9		
Unrestricted funds		<u>137,435</u>	<u>139,350</u>
TOTAL FUNDS		<u>137,435</u>	<u>139,350</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 29 June 2024 and were signed on its behalf by:



D Axtell (Chairman) - Trustee

The notes form part of these financial statements

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 exemption 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.

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.

Notes to the Financial Statements - continued
for the Year Ended 31 December 2023

2. OTHER TRADING ACTIVITIES

	2023	2022
	£	£
Fundraising events	<u>16,282</u>	<u>27,560</u>

3. INVESTMENT INCOME

	2023	2022
	£	£
Deposit account interest	<u>913</u>	<u>138</u>

4. CHARITABLE ACTIVITIES COSTS

	Direct Costs £	Support costs (see note 5) £	Totals £
Education and awareness	<u>33,267</u>	<u>28,246</u>	<u>61,513</u>

5. SUPPORT COSTS

	Management £	Finance £	Governance costs £	Totals £
Education and awareness	<u>23,044</u>	<u>3,102</u>	<u>2,100</u>	<u>28,246</u>

6. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2023 nor for the year ended 31 December 2022.

Trustees' expenses

	2023	2022
	£	£
Trustees' expenses	<u>2,696</u>	<u>1,287</u>

7. TANGIBLE FIXED ASSETS

	Computer equipment £
COST	
At 1 January 2023 and 31 December 2023	<u>4,500</u>
DEPRECIATION	
At 1 January 2023 and 31 December 2023	<u>4,500</u>
NET BOOK VALUE	
At 31 December 2023	<u>-</u>
At 31 December 2022	<u>-</u>

8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR	2023 £	2022 £
Trade creditors	5,116	-
Other creditors	2,100	1,992
	<u>7,216</u>	<u>1,992</u>

9. MOVEMENT IN FUNDS	At 1.1.23 £	Net movement in funds £	At 31.12.23 £
Unrestricted funds			
General fund	139,350	(1,915)	137,435
	<u>139,350</u>	<u>(1,915)</u>	<u>137,435</u>
TOTAL FUNDS	<u>139,350</u>	<u>(1,915)</u>	<u>137,435</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	61,959	(63,874)	(1,915)
	<u>61,959</u>	<u>(63,874)</u>	<u>(1,915)</u>
TOTAL FUNDS	<u>61,959</u>	<u>(63,874)</u>	<u>(1,915)</u>

Comparatives for movement in funds

	At 1.1.22 £	Net movement in funds £	At 31.12.22 £
Unrestricted funds			
General fund	141,849	(2,499)	139,350
	<u>141,849</u>	<u>(2,499)</u>	<u>139,350</u>
TOTAL FUNDS	<u>141,849</u>	<u>(2,499)</u>	<u>139,350</u>

9. MOVEMENT IN FUNDS - continued

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	51,735	(54,234)	(2,499)
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>51,735</u>	<u>(54,234)</u>	<u>(2,499)</u>

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

	At 1.1.22 £	Net movement in funds £	At 31.12.23 £
Unrestricted funds			
General fund	141,849	(4,414)	137,435
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>141,849</u>	<u>(4,414)</u>	<u>137,435</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	113,694	(118,108)	(4,414)
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>113,694</u>	<u>(118,108)</u>	<u>(4,414)</u>

10. RELATED PARTY DISCLOSURES

Mr Alan Peaford is a director of Aerocomm Ltd. During the year, the charity paid £3,148 (2022: £3,173) for editing and production to Aerocomm Limited.

Natalie Blockley, who is the wife of Charles Blockley, was paid £16,800 (2022: £15,800) for administration services, during the year.

CdLS Foundation UK & Ireland

England & Wales - Charity number 1054033

Accounts

**Report of the Trustees and
Unaudited Financial Statements for the Year Ended 31 December 2022
for
CDLS FOUNDATION UK & IRELAND**

**Knox Cropper LLP
Chartered Accountants
153 -155 London Road
Hemel Hempstead
Hertfordshire
HP3 9SQ**

CDLS FOUNDATION UK & IRELAND

**Contents of the Financial Statements
for the Year Ended 31 December 2022**

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CDLS FOUNDATION UK & IRELAND

Report of the Trustees for the Year Ended 31 December 2022

The trustees present their report with the financial statements of the charity for the year ended 31 December 2022. 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: 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.

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.

ACHIEVEMENT AND PERFORMANCE

This report is intended to give an overview of our activities during 2022 and an insight into the work of the Trustees:

After the hiatus during the global pandemic, we decided to return to in-person conferences in 2022. Initially it was decided to see how the Spring conference went, how well it was attended and to have the autumn one planned but pending the review of Spring. In actuality, the appetite for in-person events was very keen and both were well attended. We observed appropriate precautions against the spread of Covid-19 and nothing was reported as a problem with this on both occasions. We kept with the Saturday night entertainment and buffet evenings as well and both were well received.

We aim to have locations and dates planned a year in advance, so we returned to the long term rotation plan to cover all regions as frequently as possible and will have secured and booked a venue at least one event in advance. This means we can announce the next event at the conferences.

We continued the format for conference keynote speakers with longer sessions for each speaker and fewer speakers. Less content over the day but the feedback we were getting was that there is too much to digest. The Q&A session at the end of each address were longer and more interactive as an open forum with a moderator prompting questions and comments. Workshops in the afternoon offer more hands-on practical help and advice.

The first family weekend was held at the Crowne Plaza Hotel, Reading, April 2022. This was very well attended and all families, trustees and medical professionals were profoundly glad to see each other. As always, there were some new families as well as families who we came into contact with during the pandemic attending for the first time. There was a landmark moment in terms of changes to our Scientific, Clinical Advisory Team. We said goodbye to our clinical Geneticist and former Medical Director, Dr David FitzPatrick. This was his last appearance with us after over 20 years in the role. We thanked him, wished him a happy retirement and presented him with an engraved wine carafe as a token of our appreciation for the many years of service. We also introduced some new advisors to the team. David's successor had been introduced at the previous virtual conference. Dr Anne Lampe made her first in-person appearance as David handed over the reigns. We were also pleased to introduce our latest recruit to the team. Joe Curry is a paediatric abdominal surgeon from Great Ormond Street Hospital. He has many years of experience in this field, performing so many of the procedures that are common to our CdLS people. His advice will be invaluable and complements the clinical advice of Dr Peter Gillett with an even more comprehensive view of solutions to gastrointestinal problems. Lastly was the addition of Richard Fitzgerald, a special needs dentist. He was on hand to meet families and acclimatise to the CdLS community. He will forever be remembered for his giant toothbrush as part of his stand with information for families. He is a welcome addition to the team and will be speaking at future events. The evening buffet and quiz was a fun way to round off the day.

Our second conference, held in October 2022, was at the Hilton East Midlands Airport. This was a very convenient location for getting to. A well attended weekend once again, with at least three first time families. It was also good to see some old friends who hadn't been to a conference for a while. Dr Caroline Richards has long been one of the SCAT and it was great to hear her talks on challenging behaviour and sleep problems. The afternoon session included a workshop for the wellbeing of parents and carers of CdLS people. The Regional Volunteers programme had to be put on hold during the pandemic. We were pleased to restart the initiative and recruit new families for the roles in different areas of the country. Evening entertainment was also very well attended.

The World Federation of CdLS Support Groups should have held its two yearly World Conference in 2021. It was postponed until 2022 because of the pandemic. It did go ahead in November 2022 in Bogotá, Colombia. In attendance were professionals and volunteer/leaders from the USA, Brazil, UK, Germany, Netherlands, Poland, Switzerland, Spain, Israel and of course, Colombia. Families were present from all over Latin America.

CDLS FOUNDATION UK & IRELAND

Report of the Trustees for the Year Ended 31 December 2022

The UK was represented by Chair David Axtell and professionals Dr Peter Gilett and Professor Chris Oliver. The conference was a tremendous achievement and consisted of parallel sessions - one for families and one for scientists, rather than a dedicated scientific symposium. There were full day meetings of the Scientific Advisory Council (SAC) and the Federation Council, the latter chaired by the UK & Ireland Foundation as well as for a combined session. The SAC discussed the updating of the International Consensus Statement on Diagnosis and Management of CdLS. 2023 marks the 5th anniversary of its publication, so it is ripe for being updated. The Federation Council meeting established new ways of encouraging groups of families in new countries to establish a formal support group and join the Federation. In support of this, we were pleased to welcome representatives from Venezuela, Mexico, Peru, Costa Rica and Ecuador to the meeting.

At the AGM in Reading, the Trustees Report as well as the accounts for 2021 were presented, voted upon and accepted. Trustees David Axtell, Ginny Penney, Sara Peaford Smith, Jack Young and Ryan Saunders were re-elected. David was re-elected as Chair, Charles Blockley re-elected as Vice Chair, Ginny Penney as Hon. Secretary. The Treasurer position was at that time vacant. A new trustee, Kelly Boland was proposed, seconded and unanimously accepted. At the AGM, an appeal was made for more trustees and in particular, someone to fill the treasurer vacancy. After the meeting, Bjorn Harris volunteered to stand as a trustee. At the next meeting, he was proposed and voted in to take on the treasurer role, for which we are very grateful.

In setting a draft annual budget, the Trustees agreed a figure of £55,000 for 2022 as the amount needed to meet the Foundation objectives for the year. This is to cover paid staff, office space, conference costs, website hosting, magazine print and distribution, trustees' expenses and other administration costs. We have also allowed for payment towards the research project of a new PhD student, Beth Jones, who is researching connections between autism and anxiety in CdLS. Conference costs would show a big increase as we returned to in-person events.

To add to our fundraising strategy, we signed up for a scheme called Run for Charity. It offers a range of events that fundraisers can sign up for. As well as more serious running events, there are fun events and virtual ones, thus broadening the parameters of participation to a wider range of abilities.

As well as funding a new research project, 2022 saw the launch of a new behavioural assessment tool by the Cerebra Network for Neurodevelopmental Disorders. Designed and compiled by Professor Chris Oliver and his team, the Be-Well Checklist was launched by Cerebra in a generic form for all neurodevelopmental disorders, together with a bespoke supplement for CdLS. Designed to be used together, they form a way of checking off other factors that may affect behavioural problems and get to the root of a problem that is causing them.

We also launched an initiative to invite local professionals to conferences. The idea is that we can educate professionals better about CdLS if they can come to conferences and learn from our expert advisors. This to be managed by families who will know professionals local to a conference venue.

International CdLS Awareness Day 2022 was very successful, once again. We increased the campaign to light up buildings and monuments purple for CdLS. This was taken up across the country with many more town halls, theatres, care homes and even a castle lighting up for us. This was supported by a media campaign that got Awareness Day featured in several newspapers and their online editions.

We also had to mark the passing of Queen Elizabeth II. She would have been aware of CdLS through the awarding of an MBE to our former Chair, Alan Peaford. It was also important to be able to offer support for our CdLS people who were struggling with the national mourning and grief over the loss of a much-loved monarch.

Report compiled by Chairman David Axtell

CDLS FOUNDATION UK & IRELAND

Report of the Trustees for the Year Ended 31 December 2022

FINANCIAL REVIEW

Financial position

Total income for the year was £51,735 (2021: £45,243) of which donations amounted to £22,572 (2021: 22,801) and fundraising events £27,560 (2021: 21,901). Total expenditure for the year was £54,234 (2021: £33,220) of which £50,365 (2021: £33,004) related to charitable activities. This gave rise to net expenditure of £2,499 (2021: net income £12,023) for the year. The reserves at the end of the year amounted to £139,350 (2021: £141,849).

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)
Mrs C McCarney (Trustee)
Ms F Kett (Trustee)
R Saunders (Trustee)
Mrs S Peaford Smith (Trustee)
Mrs G Penney (Hon. Secretary)
C Blockley (Vice Chariman)
J Young (Trustee)

Independent Examiner

Knox Cropper LLP
Chartered Accountants
153 -155 London Road
Hemel Hempstead
Hertfordshire
HP3 9SQ

Approved by order of the board of trustees on 29 April 2023 and signed on its behalf by:



D Axtell (Chairman) - Trustee

**Independent Examiner's Report to the Trustees of
CdLS Foundation UK & Ireland**

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 2022.

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

Knox Cropper LLP
Chartered Accountants
153 -155 London Road
Hemel Hempstead
Hertfordshire
HP3 9SQ

Date:

29th April 2023

CDLS FOUNDATION UK & IRELAND**Statement of Financial Activities
for the Year Ended 31 December 2022**

		2022 Unrestricted fund £	2021 Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies		22,572	22,801
Charitable activities			
Education and awareness		1,465	532
Other trading activities	2	27,560	21,901
Investment income	3	138	9
Total		51,735	45,243
EXPENDITURE ON			
Raising funds		3,869	216
Charitable activities	4		
Education and awareness		50,365	33,004
Total		54,234	33,220
NET INCOME/(EXPENDITURE)		(2,499)	12,023
RECONCILIATION OF FUNDS			
Total funds brought forward		141,849	129,826
TOTAL FUNDS CARRIED FORWARD		139,350	141,849

The notes form part of these financial statements

CDLS FOUNDATION UK & IRELAND

**Balance Sheet
31 December 2022**

		2022 Unrestricted fund £	2021 Total funds £
CURRENT ASSETS	Notes		
Cash at bank		141,342	141,849
CREDITORS			
Amounts falling due within one year	8	(1,992)	-
NET CURRENT ASSETS		<u>139,350</u>	<u>141,849</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>139,350</u>	<u>141,849</u>
NET ASSETS		<u>139,350</u>	<u>141,849</u>
FUNDS	9		
Unrestricted funds		<u>139,350</u>	<u>141,849</u>
TOTAL FUNDS		<u>139,350</u>	<u>141,849</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 29 April 2023 and were signed on its behalf by:



D Axtell (Chairman) - Trustee

The notes form part of these financial statements

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.

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.

CDLS FOUNDATION UK & IRELAND

**Notes to the Financial Statements - continued
for the Year Ended 31 December 2022**

2. OTHER TRADING ACTIVITIES				
			2022	2021
			£	£
	Fundraising events		<u>27,560</u>	<u>21,901</u>
3. INVESTMENT INCOME				
			2022	2021
			£	£
	Deposit account interest		<u>138</u>	<u>9</u>
4. CHARITABLE ACTIVITIES COSTS				
		Direct Costs	Support costs (see note 5)	Totals
		£	£	£
	Education and awareness	<u>24,370</u>	<u>25,995</u>	<u>50,365</u>
5. SUPPORT COSTS				
		Management	Finance	Governance costs
		£	£	£
	Education and awareness	<u>20,969</u>	<u>2,386</u>	<u>25,995</u>
6. TRUSTEES' REMUNERATION AND BENEFITS				
There were no trustees' remuneration or other benefits for the year ended 31 December 2022 nor for the year ended 31 December 2021.				
Trustees' expenses				
			2022	2021
			£	£
	Trustees' expenses		<u>1,287</u>	<u>-</u>
7. TANGIBLE FIXED ASSETS				
				Computer equipment £
COST				
	At 1 January 2022 and 31 December 2022			<u>4,500</u>
DEPRECIATION				
	At 1 January 2022 and 31 December 2022			<u>4,500</u>
NET BOOK VALUE				
	At 31 December 2022			<u>-</u>
	At 31 December 2021			<u>-</u>

8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR	2022	2021
	£	£
Other creditors	<u>1,992</u>	<u>-</u>

9. MOVEMENT IN FUNDS		Net movement in funds	At
	At 1.1.22	in funds	31.12.22
	£	£	£
Unrestricted funds			
General fund	141,849	(2,499)	139,350
TOTAL FUNDS	<u>141,849</u>	<u>(2,499)</u>	<u>139,350</u>

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

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
General fund	51,735	(54,234)	(2,499)
TOTAL FUNDS	<u>51,735</u>	<u>(54,234)</u>	<u>(2,499)</u>

Comparatives for movement in funds

	At 1.1.21	Net movement in funds	At
	£	£	31.12.21
			£
Unrestricted funds			
General fund	129,826	12,023	141,849
TOTAL FUNDS	<u>129,826</u>	<u>12,023</u>	<u>141,849</u>

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

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
General fund	45,243	(33,220)	12,023
TOTAL FUNDS	<u>45,243</u>	<u>(33,220)</u>	<u>12,023</u>

9. MOVEMENT IN FUNDS - continued

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

	At 1.1.21 £	Net movement in funds £	At 31.12.22 £
Unrestricted funds			
General fund	129,826	9,524	139,350
TOTAL FUNDS	<u>129,826</u>	<u>9,524</u>	<u>139,350</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	96,978	(87,454)	9,524
TOTAL FUNDS	<u>96,978</u>	<u>(87,454)</u>	<u>9,524</u>

10. RELATED PARTY DISCLOSURES

Mr Alan Peaford is a director of Aerocomm Ltd. During the year, the charity paid £3,173 (2021: £3,136) for editing and production to Aerocomm Limited.

Natalie Blockley, who is the wife of Charles Blockley, was paid £15,800 (2021: £15,600) for administration services, during the year.

CdLS Foundation UK & Ireland

England & Wales - Charity number 1054033

Accounts

**Report of the Trustees and
Unaudited Financial Statements for the Year Ended 31 December 2021
for
CDLS FOUNDATION UK & IRELAND**

Knox Cropper LLP
Chartered Accountants
153 -155 London Road
Hemel Hempstead
Hertfordshire
HP3 9SQ

CDLS FOUNDATION UK & IRELAND

**Contents of the Financial Statements
for the Year Ended 31 December 2021**

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**Report of the Trustees
for the Year Ended 31 December 2021**

The trustees present their report with the financial statements of the charity for the year ended 31 December 2021. 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: 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.

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 2021**

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 affected by the global pandemic in 2021. As in 2020, we had to consider whether we could revert to in-person conferences or would have to have virtual events again. We still had the hotel in Basingstoke holding a reservation after having to postpone the event in Spring 2020, but we had to make an early decision to let that reservation go and obtain a refund of our deposit.

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. As restrictions changed throughout the year, we still kept a close eye on the number of infections with Covid-19 and considered that safety could not be risked in holding either event, as an in-person conference.

Again, we had to focus on raising awareness and ensuring that our outreach to new families remained as effective as possible, in a virtual environment. We are pleased to report that we brought many new families into the fold and could connect them with expert advice.

As more was learned about the effects of Covid and especially the new variants that emerged, we continually updated advice on how the pandemic could affect people with CdLS. We know of many CdLS people who did get Covid as restrictions were eased but thankfully, all have survived as far as we know in the UK and Ireland. Sadly, there have been deaths linked to Covid in other countries among the CdLS population.

Our behavioural psychology advisors helped us hugely with tailored advice on mental health issues, dealing with our CdLS people getting "cabin fever," with the added issue of trying to get back to normality. Representatives of the Foundation attended a workshop discussion aimed at painting a clear picture of the issues of getting back to pre-Covid conditions for people with intellectual disability.

Our usual channels of communication were on hand to provide updates to all of these issues for our families. Social media's effectiveness seemed to have levelled off because of so much being virtual. There seemed to be a fatigue developing of activity confined to being online and so many meetings on Zoom and similar platforms. However, there wasn't much alternative and these platforms are still immensely useful for getting our messages across and much more.

Rare Disease Day was a bigger splash for us in 2021. Our media campaign centred around other rare diseases as well as CdLS. The point is that separately, we may be rare. All of us working together makes us a considerable proportion of the global population. It means we can have a much bigger voice to try and facilitate change.

In place of a Spring conference for 2021, we planned a bigger online presence for International Awareness Day. Rather than repeat what we did in 2020, we planned a host of activities on our Facebook page. As well as a lead up campaign of trustees' and other family's stories, we had themed online graphics for all social media, countdown cards and started a virtual balloon race, which was sponsored by entrants as a fundraiser. The winner was announced on the day itself. We repeated one aspect which was fact cards, themed around behavioural problems in CdLS.

On the actual day, as well as the fun online activities, we played pre-recorded videos provided by our professionals, in which they answered specific questions posed by our families after we had polled them. There were live streamed introductions, cooking, cocktail making (all with a purple theme), signed storytelling, mindfulness and sensory play. The day culminated with the ever popular pub quiz. In all it was a very successful day and raised a considerable amount in funds for us. We extend our grateful thanks to all families who took part and made it such a fantastic day.

Research continued and there were many new projects that were started in 2021. The Foundation had previously agreed to part fund a new PhD programme looking at anxiety and how it links with other characteristics in CdLS such as autism. This programme could go ahead in 2021 and a student was appointed to start in October.

**Report of the Trustees
for the Year Ended 31 December 2021**

In terms of our professional advisers, some changes were announced. Our long standing member of the Scientific, Clinical Advisory Team and former Medical Director, Dr David FitzPatrick, announced that he would be retiring in 2022. He was kind enough to find a successor in a colleague from Edinburgh, Dr Anne Lampe. She is a very experienced Clinical Geneticist and will prove a worthy member of the team. In addition, we recruited Mr Joe Curry, a Paediatric Gastro-Intestinal Surgical Consultant. Joe will provide valuable advice on abdominal and other surgeries that affect our children and will work in tandem with our Medical Director and Gastroenterologist, Dr Peter Gillett.

Our Autumn conference was once more a virtual one. We used the same professional hosting platform and format as we used in 2020. We also offered to share it worldwide but in particular, we worked in association with our sister group in Israel. We had many attendees from around the world with most of the Israeli group watching on catch up for the next 3 months after the day. Registrations were on a similar level to the one in 2020. In addition to having pre-planned questions from families to inform the aspects of the talks on all of the usual areas, we had live Q&As after each. There was a presentation by Rhiann Staines who is a consultant on SEN matters and provides help with EHCP preparation and more. There was also an opportunity for David FitzPatrick to introduce his successor, Anne Lampe and announce his retirement. There was an ad hoc opportunity to do a live link up with Joe Curry, who kindly joined us during a break while on call at Great Ormond Street Hospital. We introduced him to families at the conference and welcomed both him and Anne to the team.

We worked to try and redevelop our website over the course of 2021. We produced the structure and format we require before trying to source someone to do the development work required. Initially, we looked at trying out college students on a suitable IT course to see if they could produce something viable as part of their coursework. This would have benefitted us and the students at little or no cost to the Foundation. Sadly, none of the ideas really met our criteria and the professional look we need. Another developer was sourced who could do the work at minimal cost, with main design input coming from the board. Work has begun and is developing into the site we want and need. The amount of information on the site is incredible, so this is a project that will take some years to complete.

On the World Federation front, sadly, the World Conference that was scheduled for 2021 had to be postponed due to the global pandemic. The host organisation CdLS Colombia proposed putting it back to November 2022. A Federation Council meeting was convened in November and this proposal was accepted, along with many developmental proposals. The conference hosts feel that everything will be safe enough and that travel between countries in Latin America will have opened up sufficiently to enable good attendance. A virtual aspect may well be included but it will be an in-person event.

We could not hold an AGM in person but had already amended our constitution in line with the Charity Commission guidance to allow for this.

We have planned that we will aim to revert to in-person conferences in Spring 2022. To achieve this, we polled families to see if they feel the situation will be safe enough, that there is the desire for a real event and what safety measures they would require the Foundation to put in place. It would also be a chance to formally say goodbye and thanks to David FitzPatrick as well as introduce the new members of the team.

One of our Mums, Anne Dewhurst, gave us a great idea. To produce a book of short CdLS family stories that would serve as an introduction to CdLS and the journey facing new families, in particular. The shared experiences of families old and new would be a great reassurance that you are not alone. Anne put us in touch with a publisher who she had worked with on her own book but sadly, this publisher had to pull out before we could get the book produced. In the event, we published the book ourselves on Amazon. It was just in time to order for Christmas and is now available to buy on demand.

Our planning meeting in January had to be online. Reviewing the profit made in 2020, we decided to ringfence some of that money to ensure we could fund the PhD research project and not have to be worried with ensuring we could raise the funds for this.

**Report of the Trustees
for the Year Ended 31 December 2021**

As we did not plan any in-person events in 2021, we could operate on a reduced budget which was set at £35k for the year. Income for 2021 exceeded expenditure once more. We underspent at only approx. £33k and brought in approx. £45k, down on the previous year but still giving us a profit. We continue to 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) (resigned 28.1.21)
Mrs C McCarney (Trustee)
Ms F Kett (Trustee)
R Saunders (Trustee)
Mrs S Peaford Smith (Trustee)
Mrs G Penney (Hon. Secretary)
C Blockley (Vice Chariman)
J Young (Trustee)

Independent Examiner

Knox Cropper LLP
Chartered Accountants
153 -155 London Road
Hemel Hempstead
Hertfordshire
HP3 9SQ

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 23 April 2022 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 2021.

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
Chartered Accountants
153 -155 London Road
Hemel Hempstead
Hertfordshire
HP3 9SQ

Date:

CDLS FOUNDATION UK & IRELAND**Statement of Financial Activities
for the Year Ended 31 December 2021**

		2021 Unrestricted fund £	2020 Total funds £
INCOME AND ENDOWMENTS FROM	Notes		
Donations and legacies		22,801	33,328
Charitable activities			
Education and awareness		532	955
Other trading activities	2	21,901	24,688
Investment income	3	9	1
Total		45,243	58,972
EXPENDITURE ON			
Raising funds		216	2,476
Charitable activities	4		
Education and awareness		33,004	31,336
Total		33,220	33,812
NET INCOME		12,023	25,160
RECONCILIATION OF FUNDS			
Total funds brought forward		129,826	104,666
TOTAL FUNDS CARRIED FORWARD		141,849	129,826

The notes form part of these financial statements

CDLS FOUNDATION UK & IRELAND**Balance Sheet
31 December 2021**

	Notes	2021 Unrestricted fund £	2020 Total funds £
CURRENT ASSETS			
Cash at bank		141,849	131,535
CREDITORS			
Amounts falling due within one year	8	-	(1,709)
NET CURRENT ASSETS		<u>141,849</u>	<u>129,826</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>141,849</u>	<u>129,826</u>
NET ASSETS		<u>141,849</u>	<u>129,826</u>
FUNDS	9		
Unrestricted funds		<u>141,849</u>	<u>129,826</u>
TOTAL FUNDS		<u>141,849</u>	<u>129,826</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 23 April 2022 and were signed on its behalf by:



D Axtell (Chairman) - Trustee

The notes form part of these financial statements

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.

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 2021**2. OTHER TRADING ACTIVITIES**

	2021	2020
	£	£
Fundraising events	21,901	24,688

3. INVESTMENT INCOME

	2021	2020
	£	£
Deposit account interest	9	1

4. CHARITABLE ACTIVITIES COSTS

	Direct Costs £	Support costs (see note 5) £	Totals £
Education and awareness	10,054	22,950	33,004

5. SUPPORT COSTS

	Management £	Finance £	Governance costs £	Totals £
Education and awareness	21,169	(569)	2,350	22,950

6. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2021 nor for the year ended 31 December 2020.

Trustees' expenses

	2021	2020
	£	£
Trustees' expenses	-	392

7. TANGIBLE FIXED ASSETS

	Computer equipment £
COST	
At 1 January 2021 and 31 December 2021	4,500
DEPRECIATION	
At 1 January 2021 and 31 December 2021	4,500
NET BOOK VALUE	
At 31 December 2021	-
At 31 December 2020	-

Notes to the Financial Statements - continued
for the Year Ended 31 December 2021

8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2021 £	2020 £
Other creditors	-	1,709

9. MOVEMENT IN FUNDS

	At 1.1.21 £	Net movement in funds £	At 31.12.21 £
Unrestricted funds			
General fund	129,826	12,023	141,849
TOTAL FUNDS	<u>129,826</u>	<u>12,023</u>	<u>141,849</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	45,243	(33,220)	12,023
TOTAL FUNDS	<u>45,243</u>	<u>(33,220)</u>	<u>12,023</u>

Comparatives for 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	<u>104,666</u>	<u>25,160</u>	<u>129,826</u>

Comparative 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	<u>58,972</u>	<u>(33,812)</u>	<u>25,160</u>

Notes to the Financial Statements - continued
for the Year Ended 31 December 2021

9. MOVEMENT IN FUNDS - continued

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

	At 1.1.20 £	Net movement in funds £	At 31.12.21 £
Unrestricted funds			
General fund	104,666	37,183	141,849
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>104,666</u>	<u>37,183</u>	<u>141,849</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	104,215	(67,032)	37,183
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>104,215</u>	<u>(67,032)</u>	<u>37,183</u>

10. RELATED PARTY DISCLOSURES

Mr Alan Peaford is a director of Aerocomm Ltd. During the year, the charity paid £3,136 (2020: £3,366) for editing and production to Aerocomm Limited.

Natalie Blockley, who is the wife of Charles Blockley, was paid £15,600 (2020: £15,600) for administration services, during the year.

11. 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.

CdLS Foundation UK & Ireland

England & Wales - Charity number 1054033

Accounts

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

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CDLS FOUNDATION UK & IRELAND

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

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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

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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 Chariman)

J Young (Trustee)

Independent Examiner

Knox Cropper LLP

153-155 London Road

Hemel Hempstead

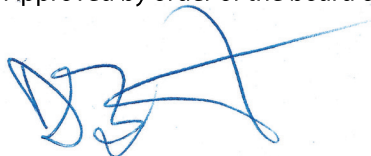
Hertfordshire

HP3 9SQ

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**

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
153-155 London Road
Hemel Hempstead
Hertfordshire
HP3 9SQ

Date:

CDLS FOUNDATION UK & IRELAND

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

	Notes	2020 Unrestricted fund £	2019 Total funds £
INCOME AND ENDOWMENTS FROM			
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			
Education and awareness	4	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

	Notes	2020 Unrestricted fund £	2019 Total funds £
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			
Unrestricted funds	10	<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.

CDLS FOUNDATION UK & IRELAND

**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	<u>4,500</u>
DEPRECIATION	
At 1 January 2020 and 31 December 2020	<u>4,500</u>
NET BOOK VALUE	
At 31 December 2020	<u>-</u>
At 31 December 2019	<u>-</u>

9. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2020 £	2019 £
Other creditors	<u>1,709</u>	<u>1,660</u>

10. MOVEMENT IN FUNDS

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

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

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

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.