

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

Knox Cropper LLP
Chartered Accountants
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**Report of the Trustees
for the Year Ended 31 December 2023**

The trustees present their report with the financial statements of the charity for the year ended 31 December 2023. 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 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

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

**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 Chairman)
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

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 2023.

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

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Hertfordshire
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29 June 2024

CDLS FOUNDATION UK & IRELAND

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

		2023 Unrestricted fund £	2022 Total funds £
INCOME AND ENDOWMENTS FROM	Notes		
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	4		
Education and awareness		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

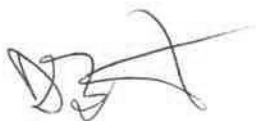
The notes form part of these financial statements

CDLS FOUNDATION UK & IRELAND

Balance Sheet
31 December 2023

		2023	2022
		Unrestricted	Total
		fund	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		137,435	139,350
TOTAL ASSETS LESS CURRENT LIABILITIES		137,435	139,350
NET ASSETS		137,435	139,350
FUNDS	9		
Unrestricted funds		137,435	139,350
TOTAL FUNDS		137,435	139,350

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
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)
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
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)
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
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)
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.