

**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**

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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', is written over a faint, light blue circular stamp or watermark.

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**

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

The notes form part of these financial statements



Balance Sheet  
31 December 2024

		2024 Unrestricted fund £	2023 Total funds £
CURRENT ASSETS	Notes		
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></u>	<u></u>
NET CURRENT ASSETS		<u>140,399</u>	<u>137,435</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		140,399	137,435
		<u></u>	<u></u>
NET ASSETS		<u>140,399</u>	<u>137,435</u>
FUNDS	10		
Unrestricted funds		140,399	137,435
		<u></u>	<u></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.

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2024**2. OTHER TRADING ACTIVITIES**

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

**3. INVESTMENT INCOME**

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

**4. CHARITABLE ACTIVITIES COSTS**

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

**5. SUPPORT COSTS**

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

**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**

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

**7. TANGIBLE FIXED ASSETS**

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

**8. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	<b>2024</b>	2023
	£	£
Prepayments and accrued income	<b>100</b>	-
	<u>100</u>	<u>-</u>

**9. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	<b>2024</b>	2023
	£	£
Trade creditors	-	5,116
Other creditors	<b>2,196</b>	2,100
	<u><b>2,196</b></u>	<u>7,216</u>

**10. MOVEMENT IN FUNDS**

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

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

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

**Comparatives for movement in funds**

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

**10. MOVEMENT IN FUNDS - continued**

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

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
General fund	61,959	(63,874)	(1,915)
	<u>        </u>	<u>        </u>	<u>        </u>
<b>TOTAL FUNDS</b>	<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 £
<b>Unrestricted funds</b>			
General fund	139,350	1,049	140,399
	<u>        </u>	<u>        </u>	<u>        </u>
<b>TOTAL FUNDS</b>	<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 £
<b>Unrestricted funds</b>			
General fund	111,215	(110,166)	1,049
	<u>        </u>	<u>        </u>	<u>        </u>
<b>TOTAL FUNDS</b>	<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.