

**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

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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.

**Report of the Trustees
for the Year Ended 31 December 2022**

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.

**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

**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 Chairman)
J Young (Trustee)

Independent Examiner

Knox Cropper LLP
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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

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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	Notes		
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		139,350	141,849
TOTAL ASSETS LESS CURRENT LIABILITIES		139,350	141,849
NET ASSETS		139,350	141,849
FUNDS	9		
Unrestricted funds		139,350	141,849
TOTAL FUNDS		139,350	141,849

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.

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 £	Totals £
Education and awareness	<u>20,969</u>	<u>2,386</u>	<u>2,640</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>

Notes to the Financial Statements - continued
for the Year Ended 31 December 2022**8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	2022	2021
	£	£
Other creditors	<u>1,992</u>	<u>-</u>

9. 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>

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>

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

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.