

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
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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
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EVENTS SINCE THE END OF THE YEAR

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

Approved by order of the board of trustees on 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		141,849	129,826
TOTAL ASSETS LESS CURRENT LIABILITIES		141,849	129,826
NET ASSETS		141,849	129,826
FUNDS	9		
Unrestricted funds		141,849	129,826
TOTAL FUNDS		141,849	129,826

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	<u>21,901</u>	<u>24,688</u>

3. INVESTMENT INCOME

	2021	2020
	£	£
Deposit account interest	<u>9</u>	<u>1</u>

4. CHARITABLE ACTIVITIES COSTS

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

5. SUPPORT COSTS

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

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	<u>-</u>	<u>392</u>

7. TANGIBLE FIXED ASSETS

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

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	129,826	12,023	141,849

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	45,243	(33,220)	12,023

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	104,666	25,160	129,826

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	58,972	(33,812)	25,160

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
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
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.