

GAND AID UK CIO - FOUNDATION ANNUAL REPORT

Legal and Administrative Services

Trustees

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Charity Number

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GAND AID UK CIO - FOUNDATION
Trustees Report
For the Year End 31 March 2024

The annual report covers 01 April 2023 to 31 March 2024 and acknowledges SORP in using its guidance to assist GAND AID UK (registered 12 April 2023) and FRS 102 for accounting purposes in compiling the report and meeting its obligations as a registered Charity Incorporated Organisation (CIO) in adopting the 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (effective 1 January 2019).'

Chair's Report
Gene Shaun Selby

The report recognises that GAND AID UK is set up for the purposes of its primary users, stakeholders and the stewardship and management of funds during and within its fundraising activities. The Charity, in its infancy, has engaged with donors, funders and financial supporters that have helped raise funds within the foundational start-up of the charity.

I am satisfied that GAND AID UK has effectively targeted appropriate audiences through the creation of a formal website and associated social media platforms, and through fundraising activities providing direct access to Trustees both online and-or in person.

I am, therefore, satisfied that GAND AID UK has created the foundation to build on its first-year achievements and will continue to remain financially viable when entering into subsequent years.

The report is compiled by the Charity's Trustees and use of a Company for financial accounting purposes, although the first-year's financial income amount falls short of formal auditing requirements.

Objectives and Activities

The objectives of the Charity remain unchanged and for:

The relief of sickness and the preservation and protection of health for the Public Benefit of people affected by or suffering from GATAD2B-ASSOCIATED NEURODEVELOPMENTAL DISORDER (GAND) and in particular but without limitation by a) providing advice, education and support for such persons and their families including the provision of service dogs b) raising awareness about GAND and providing information and advice to members of the medical profession and c) funding research into GAND and early identification and possible treatment.

In response, the Charity has created a formal website (gandaiduk.org) with associated social media access, 'get involved' contact information and useful resource links in both providing information and raising awareness.

The Charity organised a number of fundraising events in generating further awareness and subscribed to the Global 'Rare Disease' Day campaign using both the UK and European platforms.

The Charity is currently compiling a database of affected families consenting to the use of their data for medical research purposes. The Charity is continuing to work with and through a number of networks to increase its reach to those organisations and professions that are able to contribute to its charitable aims and objectives.

Public Benefit Statement

The Trustees meet on a scheduled basis to plan, review and implement the Charity's strategy with the Trustees paying due regard to the guidance on its obligations to deliver activities for the Public Benefit, as those described and issued by the Charity Commission.

The Charity is confident that it has initiated the types of activities that provides a Public Benefit through its early actions, and has put in place a foundation in which it is able to reach its intended target groups and families.

Achievement and Performance

The Charity is continuing with research into GAND Syndrome and other associated neurodevelopmental issues that are impacting UK families. And, using its personal experience and internal motivation to reach its intended audiences it is continuing to build its resource pool to support beneficiaries which in turn will help the Charity to build the necessary skills for delivery purposes.

Website

The Charity has created a formal website that provides in-depth details on (a) the rare genetic neurodevelopmental disorder (b) 'Our Story' detailing a family's GAND journey (c) resources links (d) 'Get Involved' and (e) activities and donation page. The website is continually updated with the latest news and features.

The website provides information on the most recent research i.e. "Gatad2b, associated with the neurodevelopmental syndrome GAND, plays a critical role in neurodevelopment and cortical patterning" and is permitted via open access article distributed under the terms of the Creative Commons CC BY license.

Social Media

The Charity uses Instagram to promote its activities with over 200+ followers. The use of logo-branded clothing images helps generate further communication reach through individual Facebook accounts and associated platforms.

The Charity subscribes to both the UK and European 'Rare Disease' day platforms (<https://www.rarediseaseday.org/friends/gand-aid-uk/>) and uses both platforms to promote its website. The Charity has 'become a friend' of EURODIS, which receives

funding from the European Union's Health Programme (2021-2027) to help promote the 'Rare Disease' day.

Press

The Mirror covered the Charity's founders' story "Girl, 3, gets rare diagnosis after mum noticed 'floppy' baby struggled to close her hand", which was also acknowledged and covered by the Rossendale Free Press.

Merchandise

The Charity has secured free clothing (i.e. hoodies) that carry's the GAND AID UK logo. The clothing was worn during fundraising events and activities in helping raise awareness.

Launch: Yorkshire 3 Peaks Fundraising Event

The Yorkshire 3 Peaks fundraising event was the main event both to launch the charity (media exposure) and generate income which in turn formed part of the largest donations to help kick-start the Charity's income stream. The Charity was further supported by two other UK charities ('Joining Jack' and 'Duchenne UK'), who kindly provided volunteers and promoted the event through their platforms.

Rare Disease Day (February 2024)

This annual event held in February is to promote awareness into rare diseases. The Charity's Trustees delivered a 2-day awareness campaign at their local General Practitioners and Barnsley Football Club created a feature in their match-day programme.

GAND Family Folder

With the support of Duchenne UK, the Charity has drafted a 'family information pack' that will be available both online and print, once completed.

International Networks

The Charity regularly communicates with 'Helping Hands' the United States charity for GAND Syndrome and shares its achievements, knowledge and information that impact on beneficiaries.

EURODIS, aside from the rare disease day campaign, is an organisation providing webinars on GAND Syndrome associated issues and the Charity's Trustees have accessed a number of online webinars, as part of a wider Trustees training approach.

The Charity has registered with the Cedars-Sinai Medical Centre (United States), which includes a focus into the study of rare neurogenetic disorders with an emphasis on the diagnosis of these type of disorders in patients.

Financial review

The results for the year ending are shown in the Statement of Financial Activities on page 10 and considered satisfactory by the Trustees

This is the Charity's first approach to fundraising and it will use this experience to map-out appropriate fundraising activities in achieving its financial goals.

Reserves Policy

At the year end the charity's funds were in credit by £18,781.28 consisting entirely of unrestricted funds generated through donations.

The amortisation of goodwill (£2,000) with regard to the setting-up and maintenance of the Charity in the first twelve-months will be reflected in its reserve policy with this amount being considered annual operating expenses moving forward.

Plans for Future Periods

The core objective of GAND AID UK is to identify and support UK families affected by the genetic disorder. It is continually promoting its charitable cause and establishing itself as a registered organisation and increasing its contacts with those suffering with GAND.

The Charity is committed to organising an inaugural 2025 UK-based GAND Conference specifically targeting UK families and professionals in the field of neurodevelopment provision.

It is the intention to calendar fundraising events and activities to further promote the Charity's cause and raise funds to support beneficiaries.

Inviting small grant bids from GAND-affected patients for support services i.e. physiotherapy that remain outside of mainstream provision.

To have a least one Charity-funded person complete an Animal-assisted Therapy Leader's course, to support and widen the Charity's offer to beneficiaries.

To increase the number of Trustees, as per the Charity's constitution.

Risk Management

The Trustees have reviewed their risk register (Governance, Strategic, Compliance, Operational, Financial, External and Reputational) which in turn shapes and influences the Charity in ensuring that appropriate controls are in place and to reduce exposure to misunderstanding, error and potential fraud.

Recruitment and Appointment of New Trustees

At the point of the CIO registration (i.e. application), it was stated that the nominated Trustees were best suited to initiate the CIO based both on their broader and professional experiences. At the start-up of the Charity, it was stated that no less than three (3) and no more than six (6) would be selected/elected as Trustees.

The existing Trustees are seeking to add a further three Trustees to reduce the risk of potential 'Conflicts of Interest' and will take responsibility for the appointment of Trustees in line with the Charity's constitution.

Trustee Training

The initial Trustees have prior experience of working with Charities; however, the Trustees are familiar with the Government's 'Welcome Pack' (since updated) and in particular guidance documents pertaining to:

- Charity reporting and accounting: the essentials November 2016 (CC15d)
- Internal financial controls for charities: protect your charity from fraud and loss (CC8)

In addition, the Charity has utilised the SORP navigator in downloading applicable modules selected by the Charity which in turn provided the necessary details for Charities FRS (102) purposes (Accounting and reporting by charities: the statement of recommended practice (SORP) – scope and application).

Structure, Governance and Management

GAND AID UK is a Charitable Incorporated Organisation (CIO - Foundation) governed by a constitution dated 09 August 2022. The Charity was registered on 12 April 2023 by the Charity Commission for England and Wales.

The Trustees who served during the year are:

G S Selby

R L Selby

B Carney

The day-to-day management remains the responsibility of R L Selby and B Carney with senior management G S Selby (Chair) taking responsibility for reporting purposes, policy development and financial management.

On 13 July 2023, GAND AID UK successfully applied to the Charities Aid Foundation (CAF) Bank, a banking service for over 14,000 charities.

Registered office:

25 Kings Hill Avenue,

Kings Hill, West Malling,

Kent

ME19 4JQ

Registered in England and Wales under number 1837656

The Charity deploys an enhanced security with dual authorisation needed for payment purposes.

Statement of the Trustees Responsibilities

The primary purpose of the trustees' annual report is to ensure that the charity is:

- publicly accountable to its stakeholders for the stewardship and management of the funds it holds on trust
- the report is considered a coherent document meeting the requirements of law and regulation
- it provides a fair, balanced and understandable review of the charity's structure, legal purposes, objectives, activities, financial performance and financial position
- it explains what the charity is set up to do, how it is going about it, and what is achieved as a result of its work
- assess the charity's progress against its objectives and to understand its plans in relation to its purposes.

The Trustees remain responsible for maintaining appropriate accounting records and providing financial statements in line with the Charities Act (2011), the Charity Regulations (2008) and within the articles of the Constitution in helping to reduce the vulnerability to financial fraud and irregularity.

The Trustees Report was approved on 20 January 2025 by the Board of Trustees:



Gene Shaun Selby

Trustee (Chair)

Date: 20 January 2025

Independent Examiners Report

Respective responsibilities of trustees and examiner:

The charity's trustees are responsible for the preparation of the financial statements. The charity's trustees consider that an audit is not required for this period under section 144(1) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

It is my responsibility to:

- (i) examine the financial statements under section 145 of the 2011 Act;
- (ii) to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- (iii) to state whether particular matters have come to my attention.

Foundation for Examiner Report

The examination was conducted in accordance with directives provided by the Charity Commission, that the examination included a review of the accounting records kept by the Charity and an assessment of the financial statements submitted with those records.

The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the financial statements present a 'true and fair view' and the report is limited to those matters set out in the statement below.

Independent examiner's statement

In piecing together the examination, no matters have arisen that:

(a) gives me reasonable cause to believe that in any material respect the requirements:

- (i) to maintain accounting records in accordance with section 130 of the 2011 Act; and;
- (ii) to prepare financial statements which accord with the accounting records, and comply with the accounting requirements of the 2011 Act; have not been met or
- (b) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the financial statements to be reached.

SSJ Accounting Limited
56 Millgate, Ackworth
Pontefract, West Yorkshire
WF7 7PN

For the Year End 31 March 2024**Income & Expenditure**

	Notes	Year 1
Income		£
Donations	1	18,820.70
Interest Received	2	19.58
TOTAL INCOME		18,840.28
Expenditure	3	
Bank & Finance charges		59.00
Surplus		18,781.28

The Financial Statement was approved by the Board of Trustees on 20 January 2025 and was signed on its behalf by:



Gene Shaun Selby

Trustee (Chair)

Date: 20 January 2025

Notes to the Financial Statement

1. Donations were made directly to either the CAF Bank's sort code and account number or via the Charity's Web 'donation' page that linked directly to the CAF Bank account
 - (i) This included the Charity's Launch Event which raised £14,194.38
2. Interest received was generated via the amounts held in the CAF Bank account
3. Expenditure was attributed to bank and finance charges associated with CAF Banking policies

Accounting Policies

1. Going concern:
 - (a) At the time of approving the financial statements, the Trustees consider that they have made a reasonable start within their 1st-year and maintain an expectation that the charity has generated sufficient resources to continue in operational existence for the foreseeable future.
2. Incoming resources
 - (a) Income amounts can be measured reliably with donors encouraged to pay directly into the CAF Bank account.
 - (i) These amounts remain unrestricted funds until such time that conditions are placed on funds.
 - (ii) It is not the intention to hold any 'cash in-hand' amounts.
3. Governance Costs
 - (a) To date, there is no associated expenditure with the Charity's activities or administrative services