



Gorlin Syndrome Group

Trustees report

Charity Commission number 1197282

Period under review: 1st April 2023 until 31st March 2024

Trustees report for the period 1st April 2023 until 31st March 2024

The trustees present their report together with the financial statements for the charity for the period 1st April 2023 until 31st March 2024

The financial statements have been prepared in accordance with accounting policies as set out by charity law and are based on a receipts and payments format adopted by the trustees.

1. Structure, Governance and Management

Governing Document

The charity was granted CIO (Charity Incorporated Organisation) status by the Charity Commission, England and Wales on the 22nd of December 2021.

This report covers the period from the 1st April 2023 until the period end date of the 31st March 2024, a total of 365 days. The end date is in line with previous year end dates for the charity.

The charity is administered by the executive committee comprising the chair, treasurer, secretary and five additional trustees.

Executive committee members usually hold office for 3 years but may be re-appointed for a further term(s) that may be for less than 3 years.

The Committee shall hold at least 2 ordinary executive meetings each calendar year, which are quorate if at least 3 of its members are present, and minutes will be kept.

Executive meetings held:

In the period (NB. 365 days) 1st April 2023 until 31st of March 2024, a total of 6 ordinary executive meetings were held. All of which were quorate.

Recruitment and appointment of new trustees

The Group have a written policy pertaining to the recruitment and re-election of trustees.

An annual review of the roles and responsibilities of trustees is undertaken to ensure a fair distribution of the work of the charity. This policy underlines the principle of equal opportunity within an open and efficient process of recruiting, retaining, and supervising a diverse Executive Committee.

To become a trustee, applicants are required to complete an application form including a declaration of eligibility. Following this stage, suitable applicants are invited to meet the trustees so that they can be further assessed and fully informed about the role and in turn ask questions of the trustees. All successful applicants are contacted within 48 hours and personal referees contacted.

New trustees are formally appointed at the next AGM or EGM and provided with an induction pack and training program based on individual need.

Six trustees currently form the executive committee:

Vicky Gill, Chair

Andrew Gill, Treasurer

Martin Hill

Stephen Morton, Secretary

Andrew Wilkinson

Howard Tyers

Risk management:

The trustees identify and record internal and external risks envisaged in any action, situation, or program of activities. After due consideration, action will be taken to avoid or minimise the risk. This includes not proceeding with a program. Where a risk has been identified but the benefits to Gorlin Syndrome Group or its beneficiaries are deemed worthwhile, then transfer of risk through outsourcing, insurance or other constitutional action is considered.

2. Objects:**The Gorlin Syndrome Group objects are:**

- a. The relief of sickness and the protection and preservation of the health of persons affected by Gorlin syndrome and any related conditions. This includes their families and carers but not restricted to.
- b. The advancement of the education of the medical profession and the general public into Gorlin syndrome and its implications for the family.
- c. The promotion of research into the causes, effects, treatment and management of Gorlin syndrome and to disseminate the useful results thereof.

3. Public Benefit:

The Trustees have reviewed the activities for the year to ensure they remain focused on the group's stated aims and objects and continue to deliver benefits to the public. The Trustees are satisfied that the charity's activities provide a wide public benefit.

4. Achievement and Performance:**Chair's report – Vicky Gill**

This report covers a period of time (365 days) from 1st April 2023 until the year end on the 31st of March 2024.

I am pleased to share some exciting updates from The Gorlin Syndrome Group as we reflect on another successful year, marked by significant milestones and collective achievements. The highlight of our year was undoubtedly the Annual Conference held at Crewe Hall in June. Feedback from attendees has been overwhelmingly positive, with many expressing gratitude for the opportunity to connect, share experiences, and discuss the challenges faced by those living with Gorlin Syndrome. Our medical advisers were present to provide invaluable insights into scientific developments and reassurance that the needs of our community remain a priority.

This year also saw remarkable fundraising efforts spearheaded by Andrew Gill's parachute jump, which raised an impressive £1,500. This success was complemented by various other initiatives, including birthday parties and generous donations from our supporters.

On a lighter note, we are thrilled to announce that one of our Trustees, Howard, has taken on the role of fashion designer! He is currently working on exciting new T-shirt designs that will not only promote The Gorlin Syndrome Group but also raise awareness about Gorlin syndrome itself.

In our commitment to providing resources for those newly diagnosed or seeking information

about Gorlin syndrome, we have designed and published informative leaflets. These materials aim to assist individuals during appointments and help them communicate effectively with their families.

Our collaborative efforts with organizations such as the Gorlin Syndrome Alliance in the USA continue to grow. We believe these connections will enhance our ability to raise awareness within both the medical profession and the wider public over time.

While we faced challenges with Palvella Therapeutics regarding a drug trial that did not progress beyond its second stage, we remain optimistic about ongoing projects. Notably, the Ultra-Violet Monitor Trial supported by a previous financial contribution of £5,000 is making strides under Professor Gareth Evans at Manchester University NHS Foundation Trust. A successful outcome could significantly benefit those diagnosed with Gorlin syndrome.

Social media remains a vital communication tool for us; our Facebook support group now boasts over 1,300 active users. Additionally, we have relaunched our website as part of ongoing efforts to improve how we connect with our community.

The executive committee continues its diligent work in setting and reviewing short-, medium-, and long-term goals for the organisation. I am deeply appreciative of the passion and commitment demonstrated by each Trustee over this past year as we realign our focus and move forward together.

The Gorlin Syndrome Group thrives thanks to the dedication of our volunteers—Trustees and Ambassadors—who selflessly contribute their time each year. Their unwavering support enables us to continue offering essential assistance and raising awareness about Gorlin syndrome. We are delighted to welcome new members this year who bring additional skills and perspectives that strengthen our community.

We are excited about developing roles for patient ambassadors who will help us engage more effectively with the Gorlin community by sharing authentic stories from individuals living with this condition, as we strive towards enhancing awareness and providing valuable resources for those affected by Gorlin syndrome.

Lastly, I would like to extend my heartfelt thanks to our esteemed medical advisors: Professor Gareth Evans, Catherine Harwood, Dr. John Lear, Dr. Kai-Ren Ong, Dr. Rakesh Anand, and Dr. Kate Fife for their unwavering support.

5. Financial review

Treasurer's report- Andrew Gill

Financial position

In the last 365 days, the charity recorded an income of £7075 plus £380 in interest payments totaling £7455. Expenditure was £10758 creating a deficit for the year of £3303. The amount of £4653 for the GSG conference accounted for the bulk of the spending. At the period end the total in unrestricted funds (No 1 Account 16893 + No 2 Account 16235) was £33128.


The trustees are satisfied that the reserves held are sufficient to support the ongoing work of the charity as the UK moves out of the pandemic. There are sufficient funds at the signing of these accounts to enable the charity to pay suppliers on time for the foreseeable future.

Reserves and investment policy:

The trustees have resolved to maintain surplus funds on the deposit account whilst they further develop the strategic plan for the group, post pandemic. As normal activities resume the level and use of reserves will be reviewed.

Statement of Assets and Liabilities at 31 March 2024:

Statement of Assets and Liabilities at 31 March 2024

 CHARITY COMMISSION FOR ENGLAND AND WALES	Charity Name	No (if any)		
	GORLIN SYNDROME GROUP	1197282		
For the period from 01/04/2023		To 31/03/2024		
Section A Receipts and payments				
	Unrestricted funds	Restricted funds	Endowment Funds	Total funds
	to the nearest £			
A1 Receipts				
Interest on deposit accounts	380	-	-	380
Donations	6243	-	-	6243
Fees for charitable servies	832	-	-	832
		-	-	
		-	-	
		-	-	-
Sub total (Gross income for AR)	7455	-	-	7455
A2 Asset and investment sales				
Sub total	-	-	-	-
Total receipts				
	7455	-	-	7455
A3 Payments				
Bank charges	67	-	-	67
Voluntary receipts	2848	-	-	2848
General running cost	1190	-	-	1190
Website update	2000	-	-	2000
Conference/away day	4653	-	-	4653
		-	-	4,999
Sub total	10758	-	-	10758
A4 Asset and investment purchases				
	-	-	-	-
Total payments				
	10758	-	-	10758
Net of receipts/(payments)				
	- 3303	-	-	- 3303

A5 Transfers between funds	-	-	-	-
A6 Cash funds last year end	36431	-	-	36432
Cash funds this year end	33128	-	-	33128

Section B Statement of assets and liabilities at the end of the period

Categories	Unrestricted funds	Restricted funds	Endowment funds
B1 Cash funds	33128	-	-
Sum of two Bank Accounts	-	-	-
	-	-	-
Total cash funds	33128	-	-
(agree balances with receipts and payments account(s))	O.K.		
	Unrestricted funds	Restricted funds	Endowment funds

to the nearest £

B2 Other monetary assets			
	Fund to which asset belongs	Cost (optional)	Current value (optional)
	-	-	-
B3 Investment assets			
	Fund to which asset belongs	Cost (optional)	Current value (optional)
	-	-	-
B4 Assets retained for the charity's own use			
	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			
Signed by one or two trustees on behalf of all the trustees	Print Name		Date of approval

Notes to the Accounts for the Year Ended 31 March 2024:

Accounting Policies

- These accounts have been prepared on a receipts and payments basis in accordance with the Charities Act 2011 and adopted by trustees.

b. Fund Accounting

Unrestricted Funds can be used in accordance with the charitable objects at the discretion of the trustees

Restricted Funds arise when the use of a donation or legacy is stipulated by the donor or funds are raised for a specific purpose. All Restricted Funds are used within the objects of the charity.

Donations and Legacies	01/04/2023~31/03/24
Enthuse Donors	1288
Just Giving Donors	1868
Other Donors	3087
Total	6243

Restricted Funds NIL

Payments to trustees:

There are no known related party transactions and no remuneration or expenses paid to the trustees, apart from that described above.

Reference and administration details:

Registered charity number England and Wales: 1197282

Principal address: 43 Tor View, Tregadillett, Launceston, Cornwall, PL15 7HB

Website: www.gorlingroup.org

Contact:

Stephen Morton, trustee, and secretary
64 Albatross Avenue, Strood, Rochester, Kent, ME2 2XP

Telephone: 07835368526

Email: steve@gorlingroup.org

Trustees as of the 31st of March 2024:

Vicky Gill	Chair,		
Andrew Gill	Treasurer		
Martin Hill	Trustee		
Stephen Morton	Secretary		
Andrew Williamson	Trustee	Appointed 2 nd June 2023	3-year term
Howard Tyers	Trustee	Appointed 23 rd August 2023	3-year term

Trustees resigned

John Dooher left on 10th July 2023

Samantha Severn joined on 2nd June 2023, but then left on 9th February 2024

Constitution:

CIO (Charity Incorporated Organisation)
Foundation Model 22nd December 2021

Bank:

CAF Bank
25 Kings Hill
Avenue Kings Hill
West Malling
Kent
ME19 4JQ

Date approved by trustees:

Signed:

Andrew Gill, trustee, and treasurer:

Signed:

Stephen Morton, trustee, and secretary: