

Company registration number: CE019577

Charity registration number: 1186327

The Schinzel-Giedion Syndrome Foundation

(A company limited by guarantee)

Annual Report and Financial Statements

for the Year Ended 31 March 2024

MG Audit Services Limited
Chartered Accountants and Registered Auditors
166 College Road
Harrow
Middlesex
HA1 1BH

The Schinzel-Giedion Syndrome Foundation

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The Schinzel-Giedion Syndrome Foundation

Reference and Administrative Details

| | |
|------------------------------------|--|
| Chairperson | Dr Nuala Summerfield |
| Trustees | Carina Rudolfsson Emma Hudson Dana Bradley Ms Aleksandra Blagunovski |
| Principal Office | Lowfield Hall, Poles Lane Lowfield Heath Crawley RH11 0PX The charity is incorporated in England. |
| Company Registration Number | CE019577 |
| Charity Registration Number | 1186327 |
| Independent Examiner | MG Audit Services Limited Chartered Accountants and Registered Auditors 166 College Road Harrow Middlesex HA1 1BH |

The Schinzel-Giedion Syndrome Foundation

Trustees' Report

Registered Charity Number: 1186327

Registered Charity Address:

Lowfield Hall, Poles Lane, Lowfield Heath, West Sussex, RH11 0PX, UK

Trustee Names:

- Nuala Summerfield, Founder & Chair and interim Treasurer
- Emma Hudson, Secretary
- Carina Rudolfsson, Social Media
- Aleksandra Blagunovski, Fundraising
- Dana Bradley, Community Engagement & Clinical Research

The trustees, who are directors for the purposes of company law, present the annual report together with the financial statements of the charitable company for the year ended 31 March 2024.

Objectives and activities

The Schinzel-Giedion Syndrome Foundation was created to represent children with Schinzel-Giedion Syndrome (SGS) and their families living all around the world. The Foundations' mission is to provide support to families caring for a child with SGS, to raise awareness of SGS and to facilitate and support scientific research. Our vision is for a future in which all children born with SGS will receive a rapid genetic diagnosis and have access to effective targeted therapies to ensure that they live longer, healthier and happier lives.

The Foundation is run by volunteer Trustees, the majority of whom are parents of children with SGS. The initial Trustee Board was formed from six parents who worked together to create this charity. The Trustee Board is currently composed of five individuals. Since formation of the charity, one Trustee requested to resign from the Board after serving one year as Treasurer. One Trustee resigned after serving a two year term and this role (Social Media) has been subsequently filled. One Trustee resigned after serving a two and a half year term and this role (Research & Policy) has been subsequently filled, and the role title amended to Community Engagement & Clinical Research. One Trustee resigned after serving a three and a half year term and this role (Fundraising) has been subsequently filled.

<https://sgsfoundation.org/board-of-trustees/>

The Trustee Board is supported by an expert Scientific and Medical Advisory Board composed of six individuals who are medical doctors and / or scientific researchers with relevant expertise and experience, and who offer their time to the Foundation in a voluntary capacity.

<https://sgsfoundation.org/scientific-and-medical-advisory-board/>

The Schinzel-Giedion Syndrome Foundation

Trustees' Report

How we have worked to raise awareness of SGS, to provide support to affected families and facilitate scientific research over this past year:

1. International Schinzel-Giedion Syndrome Awareness Day

The charity continues to celebrate International Schinzel-Giedion Syndrome Awareness Day on November 13th each year and we use this date as an important focus for community fundraising and awareness campaigns.

2. Website

The charity's website <https://sgsfoundation.org/> continues to provide curated, easy to understand medical information to families, as well as the general public. We have also included information specifically for medical professionals and scientific researchers to help educate about the SETBP1 mutations causing SGS. Our website now incorporates a feature to enable it to be translated into different languages to improve accessibility.

3. Social media awareness

We continue to maintain our social media accounts for the charity on Facebook (public page and private family group) and Instagram, as well as Twitter and LinkedIn, to help raise awareness, share relevant research updates, share stories about our children and help fundraise. We have found that Facebook and Instagram receive the most engagement from the international SGS community and newly diagnosed families.

<https://www.facebook.com/SchinzelGiedionSyndromeFoundation>

https://www.instagram.com/schinzel_giedion_syndrome/

https://twitter.com/foundation_sgs

<https://www.linkedin.com/company/sgs-foundation>

4. International SGS Patient Registry

The Schinzel Giedion Syndrome Foundation has an established patient registry and patient-entered natural history study on the Across HealthCare Matrix platform. The ClinGen standardised health surveys are being used to gather the medical information. Parents and caregivers sign informed consent to share their child's de-identified health data and genetic information, with clinicians and researchers to expand the knowledge and understanding of this rare genetic disorder. These standardised health surveys are available in multiple different languages to ensure increased accessibility and involvement of our international non-English speaking families in our clinical research projects. Maintaining and updating the SGS Patient Registry is an ongoing effort, and all newly diagnosed families are invited to participate.

5. Research Initiatives

We regularly meet with members of the Scientific and Medical Advisory Board to discuss the Foundation's research strategy and new opportunities. We held a two part virtual Family Meeting in November 2023 (Part 1) and December 2023 (Part 2) where we shared the Foundation's research progress to date and future strategic research plans with the SGS Community. We arranged for some of our research collaborators to speak at this Family meeting. We organised simultaneous live translation from interpreters in 7 different languages to ensure maximum community engagement and participation from our international SGS community.

The following are a list of the SGS Foundation's research initiatives (projects both completed and in progress):

The Schinzel-Giedion Syndrome Foundation

Trustees' Report

I. Biorepository

Study Leader - COMBINEDBrain (a non-profit consortium of patient advocacy groups for rare genetic neurodevelopmental disorders) in conjunction with The SGS Foundation

<https://combinedbrain.org/biorepository/>

Aim of the Study

- To collect, process and store de-identified blood samples and some other tissues e.g. tumour, and to generate and store patient derived iPSCs from individuals diagnosed with SGS.

Study Importance

- These biospecimens and iPSCs are made available to researchers internationally, to facilitate SGS research.

Study Participants

- Individuals with a genetically confirmed diagnosis of Schinzel-Giedion Syndrome.
- Unaffected sex-matched parents and siblings to be used as controls.

Expanding the SGS Biorepository is an ongoing effort, and all newly diagnosed families are invited to participate.

II. Epigenetic Signature Project

Study Leader - The Greenwood Diagnostic Labs (Greenwood, SC, USA) in partnership with London Health Science Centre, Canada.

Aim of the Study

- Develop a DNA methylation profile for SGS.

Study Importance

- An epi-signature for SGS could be a useful screening test as well as a potential biomarker to use in SGS clinical trials.

Study Participants

- Minimum of 10 blood samples are needed from individuals with genetically confirmed SGS, to run project.

Timing:

- SGS Foundation is coordinating recruitment through the SGS Biorepository, and it is anticipated that the required 10 blood samples will have been collected by end Q1 2025.

III. Speech & Language / Communication Study

Study Leader - Professor Angela Morgan, Speech Pathologist (Murdoch Children's Research Institute, Melbourne, Australia - The Centre of Research and Excellence in Speech and Language) with PhD student Lottie Morison

Aim of the Study

- Improve understanding of speech, language and communication abilities in children with SGS using genetic report information, and surveys on language, non-verbal communication, feeding and general health (this project utilised caregiver-entered health data from the SGS Registry).

Study Importance

- An improved understanding of the communication abilities of children with SGS will enable the development of better assessment tools and more targeted therapies.
- Ideally the findings can be translated into international guidelines to help clinicians, therapists, teachers and families/caregivers to support and develop communication skills in children with SGS.

Study Participants

- Caregivers of children with a confirmed genetic diagnosis of SGS; children aged 6 months & above.

Anticipated timing for publication of study results in peer reviewed medical journal - 2025

IV. Development of a Disease Concept Model

The Schinzel-Giedion Syndrome Foundation

Trustees' Report

Study Leader - Joan Kornkven - Masters student in Genetic Counselling, Vanderbilt University, Nashville Tennessee, USA in conjunction with The SGS Foundation and COMBINEDBrain (a non-profit consortium of patient advocacy groups for rare, genetic neurodevelopmental disorders).

Aim of Study

- To better understand the wide range of symptoms associated with SGS and the impact these have on children and their caregivers (concept elicitation interviews conducted with caregivers & health professionals).
- To highlight areas of SGS that need further research and to ensure that all symptoms and experiences of children with SGS are represented in the medical literature.

Study Importance

- Captures information about daily life of children with SGS, by their parents/caregivers.
- Identifies the most common and less well-known symptoms experienced by children with SGS.
- Increased understanding of the disease should help improve the healthcare management of children with SGS.
- Can inform future clinical trials evaluating new SGS-specific treatments and therapies.

Study Participants

- Parents of children with SGS, teachers and healthcare professionals with experience of SGS.

Anticipated timing for publication of study results in peer reviewed medical journal - 2025

V. Development of Standards of Care Guidelines for SGS

Study Coordinators - Costello Medical <https://www.costellomedical.com/> in conjunction with The SGS Foundation.

Aim of Study

- No Standards of Care recommendations for SGS currently exist. This study uses a modified Delphi method to assess expert opinion on screening and diagnosis, and monitoring of individuals with SGS.

Study Importance

- These recommendations will help guide clinicians and families/caregivers in care decisions to enhance quality and duration of life for individuals with SGS and facilitate shared decision-making.

Study Participants

- A multidisciplinary panel of 21 clinician experts from the USA and Europe, with experience of treating children with SGS.

Anticipated timing for publication of study results in peer reviewed medical journal - 2025

VI. Urinary Tract Anomalies Survey Study

Study Leader - Mr Feilim Murphy, Paediatric Urologist, Clinical Lead for South Thames Paediatric Surgery Networks with Aiysha Puri, senior surgical registrar, in conjunction with The SGS Foundation.

Aim of the Study

- Characterize the abnormalities seen in kidney and bladder anatomy in children with SGS.
- Understand the impact urinary tract issues have on the quality of life for affected children and their caregivers/families.

Study Importance

- The prevalence of urinary tract anomalies is very high in SGS. However, detailed information about the different urinary tract anomalies and their frequency and impact is lacking in the medical literature.
- It is important to publish this information so clinicians around the world can improve screening, diagnosis and management of these issues.

Study Participants

- Caregivers complete an IRB-approved survey on the SGS Registry (questions focus on urinary tract issues & the management strategies, tests and surgeries undergone in children with SGS).
- Caregivers upload imaging study reports (e.g. reports of ultrasound scans of kidney & bladder/urinary

tract, nuclear medicine imaging, urodynamic studies etc) for evaluation by the study investigators

Anticipated timing for publication of study results in peer reviewed medical journal - 2026

The Schinzel-Giedion Syndrome Foundation

Trustees' Report

VII. TREND Community

Study Leader - TREND Community (a digital health analytics company started by a mother of a child with a rare disease) in conjunction with The SGS Foundation.

Aim of the Study

- To analyse real-world experience data shared by parents and caregivers with each other, through questions and comments posted on the SGS Family Facebook group.
- To use this anonymized 'conversation' data to gain valuable and actionable insights into the community's perspective on living with this ultra rare disease.

Study Importance

- Another way for SGS Foundation and parents/caregivers to better understand Schinzel-Giedion Syndrome and thus advocate for their care.
- The Community Voice Report represents the collected data in an easy to understand, accessible format and can be shared with family, child's doctors, therapists & anyone else involved in their care.

Study Participants

- Caregivers participated by posting questions and interacting with other caregivers on the SGS Family Facebook group.

Community Voice Report - Data collected from February 2023 - March 2024. Report is now published and free to download from The SGS Foundation website <https://sgsfoundation.org/community-voice-report/>

VIII. GeneReviews

Study Leader - Dr Bregje van Bon and Dr Jessica Duis (co-authors and members of The SGS Foundation Scientific and Medical Advisory Board).

Aim of the Study

- GeneReviews is an international point-of-care resource for busy clinicians. It provides clinically relevant and medically actionable information for inherited conditions in a standardized journal-style format, covering diagnosis, management, and genetic counselling for patients and their families. Each chapter in GeneReviews is written by one or more experts on the specific condition or disease and goes through a rigorous editing and peer review process before being published online.

Study Importance

- This publication provides a detailed overview of the diagnosis and management of SGS to help support clinicians and health professionals to deliver optimal care for individuals affected by this rare genetic disorder.

GeneReviews for Schinzel-Giedion Syndrome was published in March 2024 and free to download from The SGS Foundation website <https://sgsfoundation.org/medical-professionals/> or directly <https://www.ncbi.nlm.nih.gov/books/NBK601394/>

6. Scientific collaborations

We have an expanding number of ongoing international research collaborations within the SGS Research Network. The majority of the research efforts that we support are externally funded through institutional / government / academic grants. In December 2020, a grant of 1.6 million Euros was awarded by the European Joint Project in Rare Disease (EJPRD) to one of our research consortia to support the development of a new therapy for Schinzel-Giedion Syndrome. As a result of this funding, a promising antisense oligonucleotide (ASO) therapy is in the advanced stages of pre-clinical development, and it is hoped that a potential clinical trial in patients with SGS could be possible in Q4 2025.

The Schinzel-Giedion Syndrome Foundation

Trustees' Report

We recognise that the biggest value and impact that we as The SGS Foundation can bring to the table is to provide written support for these researchers' grant applications, to facilitate access to patient data (genetic and health / development information and biospecimens) through our registry and biorepository projects, and to generate patient and community engagement and involvement with these vital research projects.

Externally funded research is the model that The SGS Foundation aims to support and promote, as it opens up possibilities for much larger research funding amounts than we could raise ourselves as a small volunteer-run organisation, and therefore ensures that these research collaborations are more sustainable. However, we do use community fundraising to provide smaller amounts of funding to initiate research projects to enable the generation of preliminary data that can then be used by researchers to apply for larger institutional / government / academic grants. One example of this is the seed funding that we provided for a project at University of Alabama, Huntsville, USA, which focused on discovering new targeted drug therapies for SGS (specifically designing PROTACs to degrade SETBP1). Our funding commitment partially paid for a PhD student and the data generated will now be used to support an international collaborative application for a large institutional / government grant.

We have been fortunate to be able to apply for and secure 'pro bono' support for a very important clinical research project to develop 'Standards of Care Guidelines for SGS', from a renowned medical communications company, Costello Medical. SGS is a severe neurodevelopmental disorder with complex medical comorbidities extending beyond the nervous system requiring the attention of a wide range of health professionals. To date there has been no peer-reviewed, consensus-based therapeutic guidance to care in SGS, so the objective with this project was to provide consensus on guidance of best practice for addressing these concerns. This resource, once published, will be pivotal in promoting optimal care and management of children with SGS from diagnosis, across their lifespan.

Our collaboration with COMBINEDBrain 501c3 gives us the opportunity to take part in a number of research projects at no / minimal cost to us (eg. the SGS patient registry on the AcrossHealthcare Matrix platform and the SGS Biorepository, the FDA-funded ORCA project with Duke University, USA, a Disease Concept Elicitation project for SGS with Vanderbilt University, USA).

We continue to foster research collaborations with research groups around the world to encourage more scientific study into SETBP1 mutations and their role in Schinzel-Giedion Syndrome.

7. Clinical collaborations

We are working to develop links with clinician experts who have experience treating children with SGS, mainly in UK, Europe and USA with the goal to develop a clinical network and Centres of Excellence / Expertise in SGS.

The Schinzel-Giedion Syndrome Foundation

Trustees' Report

Financial instruments

Fiscal Sponsor Rare Village - agreement signed on 23rd May 2023.

The SGS Foundation signed a fiscal sponsorship agreement with Rare Village Foundation on 23.05.2023. Rare Village Foundation is a Texas 501(c)(3) nonprofit corporation that exists to empower families in their work to pursue treatments and cures for rare childhood diseases through community education, inspiring advocacy, and timely connection to critical research that leads to the development of treatments for children confronting rare genetic diseases.

This agreement enables US donors to make donations to the SGS Foundation that are tax-deductible within the guidelines of U.S. law. Since This is important as The SGS Foundation is a charity representing the international SGS community, with a significant number of affected families living in U.S.A.

Objectives and policies

The charity's activities expose it to a number of financial risks including credit risk, cash flow risk and liquidity risk. The use of financial derivatives is governed by the charity's policies approved by the board of trustees, which provide written principles on the use of financial derivatives to manage these risks. The charity does not use derivative financial instruments for speculative purposes.

Cash flow risk

The charity's activities expose it primarily to the financial risks of changes in foreign currency exchange rates and interest rates. The charity uses foreign exchange forward contracts and interest rate swap contracts to hedge these exposures.

Interest bearing assets and liabilities are held at fixed rate to ensure certainty of cash flows.

Credit risk

The charity's principal financial assets are bank balances and cash, trade and other receivables, and investments.

The charity's credit risk is primarily attributable to its trade receivables. The amounts presented in the balance sheet are net of allowances for doubtful receivables. An allowance for impairment is made where there is an identified loss event which, based on previous experience, is evidence of a reduction in the recoverability of the cash flows.

The credit risk on liquid funds and derivative financial instruments is limited because the counterparties are banks with high credit-ratings assigned by international credit-rating agencies.

The charity has no significant concentration of credit risk, with exposure spread over a large number of counterparties and customers.

Liquidity risk

In order to maintain liquidity to ensure that sufficient funds are available for ongoing operations and future developments, the charity uses a mixture of long-term and short-term debt finance.

Further details regarding liquidity risk can be found in the Statement of accounting policies in the financial statements.

Small companies provision statement

This report has been prepared in accordance with the small companies regime under the Companies Act 2006.

The Schinzel-Giedion Syndrome Foundation

Trustees' Report

The annual report was approved by the trustees of the charity on 30 January 2025 and signed on its behalf by:



.....
Dr Nuala Summerfield
Chairperson

The Schinzel-Giedion Syndrome Foundation

Statement of Trustees' Responsibilities

The trustees (who are also the directors of The Schinzel-Giedion Syndrome Foundation for the purposes of company law) are responsible for preparing the trustees' report and the financial statements in accordance with the United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and applicable law and regulations.

Company law requires the trustees to prepare financial statements for each financial year. Under company law the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and of its incoming resources and application of resources, including its income and expenditure, for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by the trustees of the charity on 30 January 2025 and signed on its behalf by:



.....
Dr Nuala Summerfield
Chairperson

The Schinzel-Giedion Syndrome Foundation

Independent Examiner's Report to the trustees of The Schinzel-Giedion Syndrome Foundation

I report to the charity trustees on my examination of the accounts of the charity for the year ended 31 March 2024 which are set out on pages 12 to 23.

Respective responsibilities of trustees and examiner

As the charity's trustees of The Schinzel-Giedion Syndrome Foundation (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of The Schinzel-Giedion Syndrome Foundation are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of The Schinzel-Giedion Syndrome Foundation as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)].

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.

GAFernandes

.....
Gavin Fernandes FCA, CTA
Chartered Accountants and Registered Auditors

166 College Road
Harrow
Middlesex
HA1 1BH

30 January 2025

The Schinzel-Giedion Syndrome Foundation

Statement of Financial Activities for the Year Ended 31 March 2024 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

| | Note | Unrestricted funds £ | Restricted funds £ | Total 2024 £ |
|------------------------------------|------|----------------------------|--------------------------|--------------------|
| Income and Endowments from: | | | | |
| Donations and legacies | 3 | 84,306 | 1,197 | 85,503 |
| Total income | | 84,306 | 1,197 | 85,503 |
| Expenditure on: | | | | |
| Charitable activities | 4 | (59,106) | (5,777) | (64,883) |
| Total expenditure | | (59,106) | (5,777) | (64,883) |
| Net income/(expenditure) | | 25,200 | (4,580) | 20,620 |
| Transfers between funds | | 2,788 | (2,788) | - |
| Net movement in funds | | 27,988 | (7,368) | 20,620 |
| Reconciliation of funds | | | | |
| Total funds brought forward | | 58,537 | 35,335 | 93,872 |
| Total funds carried forward | 10 | 86,525 | 27,967 | 114,492 |
| | Note | Unrestricted funds £ | Restricted funds £ | Total 2023 £ |
| Income and Endowments from: | | | | |
| Donations and legacies | 3 | 21,134 | 35,467 | 56,601 |
| Total income | | 21,134 | 35,467 | 56,601 |
| Expenditure on: | | | | |
| Charitable activities | 4 | (2,132) | (132) | (2,264) |
| Total expenditure | | (2,132) | (132) | (2,264) |
| Net income | | 19,002 | 35,335 | 54,337 |
| Net movement in funds | | 19,002 | 35,335 | 54,337 |
| Reconciliation of funds | | | | |
| Total funds brought forward | | 39,535 | - | 39,535 |
| Total funds carried forward | 10 | 58,537 | 35,335 | 93,872 |

All of the charity's activities derive from continuing operations during the above two periods.
The funds breakdown for 2023 is shown in note 10.

The Schinzel-Giedion Syndrome Foundation

(Registration number: CE019577)
Balance Sheet as at 31 March 2024

| | Note | 2024 £ | 2023 £ |
|---|------|----------------|----------------|
| Current assets | | | |
| Debtors | 8 | 56,324 | 32,568 |
| Cash at bank and in hand | | <u>59,188</u> | <u>62,324</u> |
| | | 115,512 | 94,892 |
| Creditors: Amounts falling due within one year | 9 | <u>(1,020)</u> | <u>(1,020)</u> |
| Net assets | | <u>114,492</u> | <u>93,872</u> |
| Funds of the charity: | | | |
| Restricted funds | | 27,967 | 35,335 |
| Unrestricted income funds | | | |
| Unrestricted funds | | <u>86,525</u> | <u>58,537</u> |
| Total funds | 10 | <u>114,492</u> | <u>93,872</u> |

For the financial year ending 31 March 2024 the charity was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Directors' responsibilities:

- The members have not required the charity to obtain an audit of its accounts for the year in question in accordance with section 476; and
- The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

For the financial year ending 31 March 2024 the charity was entitled to exemption from audit under section 480 of the Companies Act 2006 relating to dormant companies.

Directors' responsibilities:

- The members have not required the charity to obtain an audit of its accounts for the year in question in accordance with section 476; and
- The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The Schinzel-Giedion Syndrome Foundation

(Registration number: CE019577)
Balance Sheet as at 31 March 2024

The financial statements on pages 12 to 23 were approved by the trustees, and authorised for issue on 30 January 2025 and signed on their behalf by:



.....
Dr Nuala Summerfield
Chairperson

The Schinzel-Giedion Syndrome Foundation

Notes to the Financial Statements for the Year Ended 31 March 2024

1 Charity status

The charity is limited by guarantee, incorporated in England, and consequently does not have share capital. Each of the trustees is liable to contribute an amount not exceeding £Nil towards the assets of the charity in the event of liquidation.

The address of its registered office is:

Lowfield Hall, Poles Lane

Lowfield Heath

Crawley

RH11 0PX

These financial statements were authorised for issue by the trustees on 30 January 2025.

2 Accounting policies

Summary of significant accounting policies and key accounting estimates

The principal accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all the years presented, unless otherwise stated.

Statement of compliance

The financial statements have been prepared in accordance with 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 2015) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102). They also comply with the Companies Act 2006 and Charities Act 2011.

Basis of preparation

The Schinzel-Giedion Syndrome Foundation meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

Going concern

The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern nor any significant areas of uncertainty that affect the carrying value of assets held by the charity.

Exemption from preparing a cash flow statement

The charity opted to early adopt Bulletin 1 published on 2 February 2016 and have therefore not included a cash flow statement in these financial statements.

Income and endowments

All income is recognised once the charity has entitlement to the income, it is probable that the income will be received and the amount of the income receivable can be measured reliably.

The Schinzel-Giedion Syndrome Foundation

Notes to the Financial Statements for the Year Ended 31 March 2024

Donations and legacies

Donations are recognised when the charity has been notified in writing of both the amount and settlement date. In the event that a donation is subject to conditions that require a level of performance by the charity before the charity is entitled to the funds, the income is deferred and not recognised until either those conditions are fully met, or the fulfilment of those conditions is wholly within the control of the charity and it is probable that these conditions will be fulfilled in the reporting period.

Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Charitable activities

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Grant provisions

Provisions for grants are made when the intention to make a grant has been communicated to the recipient but there is uncertainty about either the timing of the grant or the amount of grant payable.

Support costs

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

Taxation

The charity is considered to pass the tests set out in Paragraph 1 Schedule 6 of the Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes. Accordingly, the charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

Trade debtors

Trade debtors are amounts due from customers for merchandise sold or services performed in the ordinary course of business.

Trade debtors are recognised initially at the transaction price. They are subsequently measured at amortised cost using the effective interest method, less provision for impairment. A provision for the impairment of trade debtors is established when there is objective evidence that the charity will not be able to collect all amounts due according to the original terms of the receivables.

The Schinzel-Giedion Syndrome Foundation

Notes to the Financial Statements for the Year Ended 31 March 2024

Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

Trade creditors

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of business from suppliers. Accounts payable are classified as current liabilities if the charity does not have an unconditional right, at the end of the reporting period, to defer settlement of the creditor for at least twelve months after the reporting date. If there is an unconditional right to defer settlement for at least twelve months after the reporting date, they are presented as non-current liabilities.

Trade creditors are recognised initially at the transaction price and subsequently measured at amortised cost using the effective interest method.

Borrowings

Interest-bearing borrowings are initially recorded at fair value, net of transaction costs. Interest-bearing borrowings are subsequently carried at amortised cost, with the difference between the proceeds, net of transaction costs, and the amount due on redemption being recognised as a charge to the Statement of Financial Activities over the period of the relevant borrowing.

Interest expense is recognised on the basis of the effective interest method and is included in interest payable and similar charges.

Borrowings are classified as current liabilities unless the charity has an unconditional right to defer settlement of the liability for at least twelve months after the reporting date.

The Schinzel-Giedion Syndrome Foundation

Notes to the Financial Statements for the Year Ended 31 March 2024

Foreign exchange

Transactions in foreign currencies are recorded at the rate of exchange at the date of the transaction. Monetary assets and liabilities denominated in foreign currencies at the balance sheet date are reported at the rates of exchange prevailing at that date.

The results of overseas operations are translated at the average rates of exchange during the period and their balance sheets at the rates ruling at the balance sheet date. Exchange differences arising on translation of the opening net assets and results of overseas operations are reported in other comprehensive income and accumulated in equity (attributed to non-controlling interests as appropriate).

Other exchange differences are recognised in the Statement of Financial Activities in the period in which they arise except for:

- 1) exchange differences on transactions entered into to hedge certain foreign currency risks (see above);
- 2) exchange differences arising on gains or losses on non-monetary items which are recognised in other comprehensive income; and
- 3) in the case of the consolidated financial statements, exchange differences on monetary items receivable from or payable to a foreign operation for which settlement is neither planned nor likely to occur (therefore forming part of the net investment in the foreign operation), which are recognised in other comprehensive income and reported under equity.

Fund structure

Unrestricted income funds are general funds that are available for use at the trustees's discretion in furtherance of the objectives of the charity.

Restricted income funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Financial instruments

Classification

Financial assets and financial liabilities are recognised when the charity becomes a party to the contractual provisions of the instrument.

Financial liabilities and equity instruments are classified according to the substance of the contractual arrangements entered into. An equity instrument is any contract that evidences a residual interest in the assets of the charity after deducting all of its liabilities.

The Schinzel-Giedion Syndrome Foundation

Notes to the Financial Statements for the Year Ended 31 March 2024

Recognition and measurement

All financial assets and liabilities are initially measured at transaction price (including transaction costs), except for those financial assets classified as at fair value through profit or loss, which are initially measured at fair value (which is normally the transaction price excluding transaction costs), unless the arrangement constitutes a financing transaction. If an arrangement constitutes a financing transaction, the financial asset or financial liability is measured at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Financial assets and liabilities are only offset in the statement of financial position when, and only when there exists a legally enforceable right to set off the recognised amounts and the charity intends either to settle on a net basis, or to realise the asset and settle the liability simultaneously.

Financial assets are derecognised when and only when a) the contractual rights to the cash flows from the financial asset expire or are settled, b) the charity transfers to another party substantially all of the risks and rewards of ownership of the financial asset, or c) the charity, despite having retained some, but not all, significant risks and rewards of ownership, has transferred control of the asset to another party.

Financial liabilities are derecognised only when the obligation specified in the contract is discharged, cancelled or expires.

The Schinzel-Giedion Syndrome Foundation

Notes to the Financial Statements for the Year Ended 31 March 2024

Debt instruments

Debt instruments which meet the following conditions are subsequently measured at amortised cost using the effective interest method:

(a) The contractual return to the holder is (i) a fixed amount; (ii) a positive fixed rate or a positive variable rate; or (iii) a combination of a positive or a negative fixed rate and a positive variable rate.

(b) The contract may provide for repayments of the principal or the return to the holder (but not both) to be linked to a single relevant observable index of general price inflation of the currency in which the debt instrument is denominated, provided such links are not leveraged.

(c) The contract may provide for a determinable variation of the return to the holder during the life of the instrument, provided that (i) the new rate satisfies condition (a) and the variation is not contingent on future events other than (1) a change of a contractual variable rate; (2) to protect the holder against credit deterioration of the issuer; (3) changes in levies applied by a central bank or arising from changes in relevant taxation or law; or (ii) the new rate is a market rate of interest and satisfies condition (a).

(d) There is no contractual provision that could, by its terms, result in the holder losing the principal amount or any interest attributable to the current period or prior periods.

(e) Contractual provisions that permit the issuer to prepay a debt instrument or permit the holder to put it back to the issuer before maturity are not contingent on future events, other than to protect the holder against the credit deterioration of the issuer or a change in control of the issuer, or to protect the holder or issuer against changes in levies applied by a central bank or arising from changes in relevant taxation or law.

(f) Contractual provisions may permit the extension of the term of the debt instrument, provided that the return to the holder and any other contractual provisions applicable during the extended term satisfy the conditions of paragraphs (a) to (c).

Debt instruments that are classified as payable or receivable within one year on initial recognition and which meet the above conditions are measured at the undiscounted amount of the cash or other consideration expected to be paid or received, net of impairment.

With the exception of some hedging instruments, other debt instruments not meeting these conditions are measured at fair value through profit or loss.

Commitments to make and receive loans which meet the conditions mentioned above are measured at cost (which may be nil) less impairment.

Investments

Investments in non-convertible preference shares and non-puttable ordinary or preference shares (where shares are publicly traded or their fair value is reliably measurable) are measured at fair value through profit or loss. Where fair value cannot be measured reliably, investments are measured at cost less impairment.

Investments in subsidiaries and associates are measured at cost less impairment. For investments in subsidiaries acquired for consideration including the issue of shares qualifying for merger relief, cost is measured by reference to the nominal value of the shares issued plus fair value of other consideration. Any premium is ignored.

The Schinzel-Giedion Syndrome Foundation

Notes to the Financial Statements for the Year Ended 31 March 2024

Derivative financial instruments

The charity uses derivative financial instruments to reduce exposure to foreign exchange risk and interest rate movements. The charity does not hold or issue derivative financial instruments for speculative purposes.

Derivatives are initially recognised at fair value at the date a derivative contract is entered into and are subsequently remeasured to their fair value at each reporting date. The resulting gain or loss is recognised in statement of financial activities immediately unless the derivative is designated and effective as a hedging instrument, in which event the timing of the recognition in statement of financial activities depends on the nature of the hedge relationship.

Fair value measurement

The best evidence of fair value is a quoted price for an identical asset in an active market. When quoted prices are unavailable, the price of a recent transaction for an identical asset provides evidence of fair value as long as there has not been a significant change in economic circumstances or a significant lapse of time since the transaction took place. If the market is not active and recent transactions of an identical asset on their own are not a good estimate of fair value, the fair value is estimated by using a valuation technique.

3 Income from donations and legacies

| | Unrestricted funds | Restricted funds | Total 2024 | Total 2023 |
|----------------------------|-------------------------------|-----------------------------|-----------------------|-----------------------|
| | General £ | £ | £ | £ |
| Donations and legacies; | | | | |
| Donations from individuals | 84,306 | 1,197 | 85,503 | 56,601 |
| | <u>84,306</u> | <u>1,197</u> | <u>85,503</u> | <u>56,601</u> |

4 Expenditure on charitable activities

| | Unrestricted funds | Restricted funds | Total 2024 | Total 2023 |
|-----------------------|-------------------------------|-----------------------------|-----------------------|-----------------------|
| | General £ | £ | £ | £ |
| Note | | | | |
| Charitable Activities | 59,106 | 5,777 | 64,883 | 2,264 |
| | <u>59,106</u> | <u>5,777</u> | <u>64,883</u> | <u>2,264</u> |

The Schinzel-Giedion Syndrome Foundation

Notes to the Financial Statements for the Year Ended 31 March 2024

5 Trustees remuneration and expenses

No trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

6 Independent examiner's remuneration

| | 2024 £ | 2023 £ |
|-------------------------------------|-----------|-----------|
| Independent Examiner's remuneration | 1,020 | 1,020 |

7 Taxation

The charity is a registered charity and is therefore exempt from taxation.

8 Debtors

| | 2024 £ | 2023 £ |
|---------------|---------------|---------------|
| Other debtors | <u>56,324</u> | <u>32,568</u> |

9 Creditors: amounts falling due within one year

| | 2024 £ | 2023 £ |
|----------|--------------|--------------|
| Accruals | <u>1,020</u> | <u>1,020</u> |

10 Funds

| | Balance at 1 April 2023 £ | Incoming resources £ | Resources expended £ | Transfers £ | Balance at 31 March 2024 £ |
|---------------------------|------------------------------------|----------------------------|----------------------------|----------------|-------------------------------------|
| Unrestricted funds | | | | | |
| General | (58,537) | (84,306) | 59,106 | (2,788) | (86,525) |
| Restricted funds | <u>(35,335)</u> | <u>(1,197)</u> | <u>5,777</u> | <u>2,788</u> | <u>(27,967)</u> |
| Total funds | <u>(93,872)</u> | <u>(85,503)</u> | <u>64,883</u> | <u>-</u> | <u>(114,492)</u> |

The Schinzel-Giedion Syndrome Foundation

Notes to the Financial Statements for the Year Ended 31 March 2024

| | Balance at 1 April 2022 £ | Incoming resources £ | Resources expended £ | Balance at 31 March 2023 £ |
|---------------------------|---------------------------------|----------------------------|----------------------------|-------------------------------------|
| Unrestricted funds | | | | |
| General | (39,535) | (21,134) | 2,132 | (58,537) |
| Restricted funds | <u>-</u> | <u>(35,467)</u> | <u>132</u> | <u>(35,335)</u> |
| Total funds | <u>(39,535)</u> | <u>(56,601)</u> | <u>2,264</u> | <u>(93,872)</u> |

11 Analysis of net assets between funds

| | Unrestricted funds | Restricted funds | Total funds |
|---------------------|-----------------------|---------------------|----------------|
| | General £ | £ | £ |
| Current assets | 59,281 | 56,231 | 115,512 |
| Current liabilities | <u>(1,020)</u> | <u>-</u> | <u>(1,020)</u> |
| Total net assets | <u>58,261</u> | <u>56,231</u> | <u>114,492</u> |

| | Unrestricted funds | Restricted funds | Total funds |
|---------------------|-----------------------|---------------------|----------------|
| | General £ | £ | £ |
| Current assets | 62,344 | 32,548 | 94,892 |
| Current liabilities | <u>(1,020)</u> | <u>-</u> | <u>(1,020)</u> |
| Total net assets | <u>61,324</u> | <u>32,548</u> | <u>93,872</u> |

12 Analysis of net funds

| | At 1 April 2023 £ | Cash flow £ | At 31 March 2024 £ |
|--------------------------|----------------------|----------------|--------------------------|
| Cash at bank and in hand | 62,324 | (3,136) | 59,188 |
| Net debt | <u>62,324</u> | <u>(3,136)</u> | <u>59,188</u> |

The Schinzel-Giedion Syndrome Foundation

Detailed Statement of Financial Activities for the Year Ended 31 March 2024

| | 2024 | | 2024 | |
|--|--------------------|------------------|----------|------------|
| | Unrestricted funds | Restricted funds | Total | Total 2023 |
| | General £ | £ | £ | £ |
| Income and Endowments from: | | | | |
| Donations and legacies (analysed below) | 84,306 | 1,197 | 85,503 | 56,601 |
| Total income | 84,306 | 1,197 | 85,503 | 56,601 |
| Expenditure on: | | | | |
| Charitable activities (analysed below) | (59,106) | (5,777) | (64,883) | (2,264) |
| Total expenditure | (59,106) | (5,777) | (64,883) | (2,264) |
| Net income/(expenditure) | 25,200 | (4,580) | 20,620 | 54,337 |
| Transfers between funds (analysed below) | 2,788 | (2,788) | - | - |
| Net movement in funds | 27,988 | (7,368) | 20,620 | 54,337 |
| Reconciliation of funds | | | | |
| Total funds brought forward | 58,537 | 35,335 | 93,872 | 39,535 |
| Total funds carried forward | 86,525 | 27,967 | 114,492 | 93,872 |

The Schinzel-Giedion Syndrome Foundation

Detailed Statement of Financial Activities for the Year Ended 31 March 2024

| | 2024 | | 2024 | |
|-------------------------------|--------------------|--------------------|---------------|---------------|
| | Unrestricted funds | | | Total 2023 |
| | General £ | Restricted funds £ | Total £ | £ |
| Donations and legacies | | | | |
| Appeals and donations | - | 1,197 | 1,197 | 35,467 |
| Appeals and donations | 84,306 | - | 84,306 | 21,134 |
| | <u>84,306</u> | <u>1,197</u> | <u>85,503</u> | <u>56,601</u> |

| | 2024 | | 2024 | |
|---------------------------------|--------------------|--------------------|-----------------|----------------|
| | Unrestricted funds | | | Total 2023 |
| | General £ | Restricted funds £ | Total £ | £ |
| Charitable activities | | | | |
| Direct costs | (6,738) | - | (6,738) | (2,788) |
| Computer and website costs | (883) | - | (883) | (805) |
| Trade subscriptions | (420) | - | (420) | (216) |
| Research funding | - | (3,855) | (3,855) | - |
| Research and development | (49,997) | - | (49,997) | - |
| Accountancy fees | (1,020) | - | (1,020) | (1,020) |
| Bank charges | - | (111) | (111) | (132) |
| Foreign currency (gains)/losses | - | (1,811) | (1,811) | - |
| Foreign currency (gains)/losses | (48) | - | (48) | 2,697 |
| | <u>(59,106)</u> | <u>(5,777)</u> | <u>(64,883)</u> | <u>(2,264)</u> |

| | 2024 | | 2024 | |
|------------------------------------|--------------------|--------------------|----------|------------|
| | Unrestricted funds | | | Total 2023 |
| | General £ | Restricted funds £ | Total £ | £ |
| Transfers between funds | | | | |
| Funds - Transfer from another fund | - | (2,788) | (2,788) | - |
| Funds - Transfer from another fund | 2,788 | - | 2,788 | - |
| | <u>2,788</u> | <u>(2,788)</u> | <u>-</u> | <u>-</u> |