

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 period from 13 November 2019 to 31 March 2021

MG Audit Services Ltd
Chartered Accountants and Registered Auditors
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166 College Road
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The Schinzel-Giedion Syndrome Foundation

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The Schinzel-Giedion Syndrome Foundation

Reference and Administrative Details

Chairperson	Dr Nuala Summerfield
Trustees	Ms Adrienne Woods Ms Charla Andersen Ms Carina Rudolfsson Ms Emma Hudson
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	Gavin Fernandes FCA MG Audit Services Ltd Chartered Accountants and Registered Auditors 3rd Floor 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
- Jennifer Wagner, Social Media
- Charla Andersen, Fundraising
- Adrianne Woods, Policy and 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 period ended 31 March 2021.

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, all of whom are currently parents of children with SGS. The initial Trustee Board was formed from six parents who worked together to create this charity. One Trustee requested to resign from the Board after serving one year as Treasurer, due to lack of time to commit to the role. The Trustee Board is currently composed of five parents and is supported by an expert Scientific and Medical Advisory Board (in a voluntary capacity).

The Schinzel-Giedion Syndrome Foundation

Trustees' Report

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

1. International Schinzel-Giedion Syndrome Awareness Day

The charity has had a very positive first year. November 13th 2020 marked the first anniversary of the charity's formation and the decision was made to celebrate this date by naming it 'International Schinzel-Giedion Syndrome Awareness Day', which will now be a key annual awareness and fundraising date for the SGS community. The charity's first anniversary and the International Schinzel-Giedion Syndrome Awareness Day was featured in Rare Revolution Magazine which has a large international readership

<https://edition.pagesuite-professional.co.uk/html5/reader/production/default.aspx?pubname=&edid=30b5befa-0abe-41ee-ac2c-0b61d1363df5&pnum=92>

2. Website and e-newsletter

We have worked hard to create the charity's website <https://sgsfoundation.org/> 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. We have also started a quarterly e- newsletter which is sent out by email and is also available on our website.

3. Social media awareness

We have created social media accounts for the charity on Facebook, Instagram, Twitter and LinkedIn to help raise awareness, share relevant research updates, share stories about our children and help fundraise:

<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 is partnering with Across Healthcare Matrix to create the first international patient registry for SGS. The platform we are using will help families caring for a child with SGS to manage and organise all of their child's health information securely in one place. By joining this registry and participating in health surveys, SGS families will be playing a very important role in advancing our knowledge of this rare condition. Less than 100 children worldwide have been diagnosed with SGS so there is so much more to learn. The vital information in this registry will help researchers understand the most important features of SGS so that they can work towards developing effective therapies for our children.

The Schinzel-Giedion Syndrome Foundation

Trustees' Report

5. Research

We have made great progress over the past year in terms of engaging expert scientific researchers at leading international academic establishments to raise the profile of Schinzel-Giedion Syndrome and the SETBP1-causative mutations. This hard work has paid off and we have just received the incredible news that over €2Million of European grant funding has been awarded to an international group of research collaborators to work together to find effective, targeted epilepsy treatments for SGS. This is the first major funding awarded for SGS-specific research. This is also important because the same SETBP1 gene mutations that cause SGS in children can also cause certain difficult to treat leukaemias in adults, and so our hope is that through this SGS research we may learn more about these SETBP1 mutations and how they drive cancer, thus advancing rare cancer research too. Our press release about this grant funding is available to read on our website <https://sgsfoundation.org/schinzel-giedion-syndrome-receives-research-grant/>

Financial instruments

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.

The Schinzel-Giedion Syndrome Foundation

Trustees' Report

The annual report was approved by the trustees of the charity on 17 January 2022 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 period. 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 17 January 2022 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 2021 which are set out on pages 8 to 16.

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.

GA Fernandes

MR GAVIN FERNANDES FCA - INDEPENDENT EXAMINER

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MG Audit Services Ltd
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166 College Road
Harrow
Middlesex
HA1 1BH

18 January 2022

The Schinzel-Giedion Syndrome Foundation

Statement of Financial Activities for the Period from 13 November 2019 to 31 March 2021 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted funds £	Total 31 March 2021 £
Income and Endowments from:			
Donations and legacies	3	29,260	29,260
Total income		<u>29,260</u>	<u>29,260</u>
Expenditure on:			
Charitable activities	4	(1,793)	(1,793)
Total expenditure		<u>(1,793)</u>	<u>(1,793)</u>
Net income		<u>27,467</u>	<u>27,467</u>
Reconciliation of funds			
Total funds carried forward	7	<u><u>27,467</u></u>	<u><u>27,467</u></u>

All of the charity's activities derive from continuing operations during the above period.

The Schinzel-Giedion Syndrome Foundation

(Registration number: CE019577)
Balance Sheet as at 31 March 2021

	Note	31 March 2021 £
Current assets		
Cash at bank and in hand		<u>27,467</u>
Funds of the charity:		
Unrestricted income funds		
Unrestricted funds		<u>27,467</u>
Total funds	7	<u>27,467</u>

For the financial period ending 31 March 2021 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 period 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 financial statements on pages 8 to 16 were approved by the trustees, and authorised for issue on 17 January 2022 and signed on their behalf by:



.....
Dr Nuala Summerfield
Chairperson

The Schinzel-Giedion Syndrome Foundation

Notes to the Financial Statements for the Period from 13 November 2019 to 31 March 2021

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 20 December 2021.

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 Period from 13 November 2019 to 31 March 2021

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.

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.

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.

The Schinzel-Giedion Syndrome Foundation

Notes to the Financial Statements for the Period from 13 November 2019 to 31 March 2021

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.

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.

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 Period from 13 November 2019 to 31 March 2021

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 Period from 13 November 2019 to 31 March 2021

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 Period from 13 November 2019 to 31 March 2021

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	Total
	General	31 March
	£	2021
		£
Donations and legacies;		
Donations from individuals	29,260	29,260
	<u>29,260</u>	<u>29,260</u>

4 Expenditure on charitable activities

	Activity support costs	Total
	£	31 March
		2021
		£
Bank charges	23	23
Stationary	72	72
Trade subscriptions	591	591
Advertising	102	102
Computer and website costs	1,005	1,005
	<u>1,793</u>	<u>1,793</u>

£1,793 of the above expenditure was attributable to unrestricted funds and £Nil to restricted funds.

The Schinzel-Giedion Syndrome Foundation

Notes to the Financial Statements for the Period from 13 November 2019 to 31 March 2021

5 Trustees remuneration and expenses

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

6 Taxation

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

7 Funds

	Incoming resources £	Resources expended £	Balance at 31 March 2021 £
Unrestricted funds			
General	<u>(29,260)</u>	<u>1,793</u>	<u>(27,467)</u>

8 Analysis of net assets between funds

	Unrestricted funds General £	Total funds £
Current assets	<u>27,467</u>	<u>27,467</u>

9 Analysis of net funds

	At 13 November 2019 £	Cash flow £	At 31 March 2021 £
Cash at bank and in hand	-	27,467	27,467
Net debt	<u>-</u>	<u>27,467</u>	<u>27,467</u>

