

THE THALIDOMIDE TRUST

England & Wales · Charity number 266220

Details

Other names	THE THALIDOMIDE CHILDREN'S TRUST, THE THALIDOMIDE TRUST
Status	Registered
Legal form	Other
Registered	1973-08-07
Register	View on the Charity Commission register

Contact

Address	Thalidomide Trust 1 Eaton Court Road Colmworth Business Park Eaton Socon St. Neots PE19 8ER
Phone	01480474074
Email	hello@thalidomidetrust.org
Website	www.thalidomidetrust.org

Activities

Objects: THE CARE, WELFARE, TREATMENT AND EDUCATION OF OR OTHERWISE IN ANY WAY FOR THE RELIEF OF THE DISABILITIES OF OR TO MEET THE NEEDS OF CHILDREN SUFFERING FROM CONGENITAL DISABILITY DUE TO THALIDOMIDE.

Activities: The Thalidomide Trust provides relief and assistance to its beneficiaries through financial assistance and support services.

Classification

- **How:** Makes Grants To Individuals, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** Disability
- **Who:** People With Disabilities

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-09-30	£28,619,000	£38,137,000	£145,401,000	22
2024-09-30	£30,164,000	£39,452,000	£142,456,000	21
2023-09-30	£29,801,000	£68,084,000	£132,800,000	19
2022-09-30	£31,039,000	£34,072,000	£157,810,000	19
2021-09-30	£27,195,000	£32,854,000	£174,636,000	18
2020-09-30	£28,464,000	£32,315,000	£140,789,000	18

Trustees

Name	Role	Appointed
THALIDOMIDE TRUST COMPANY		2018-01-31

THE THALIDOMIDE TRUST

England & Wales - Charity number 266220

Accounts

The Thalidomide Trust

Annual Report and Financial Statements
for the year ended 30 September 2025

Registered Charity Number 266220

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Reference and administrative details

Registered Name	The Thalidomide Trust
Charity number	266220
Registered address	1 Eaton Court Road Eaton Socon St Neots Cambridgeshire PE19 8ER
Corporate Trustee	The Thalidomide Trust Company (incorporated on 19 January 2018 with Company Number 11160424, registered address as above)

Directors of the Corporate Company

The Directors of The Thalidomide Trust Company during the year and up to the date of approval were:

Mark Spofforth OBE BSc FCA CTA FRSA (Chair of Trustees) – retired
31 December 2024

David Body MA Solicitor of Senior Courts of England & Wales (Chair
of Trustees from 1 January 2025)

Mark Benstead MA MBA

Professor Adrian Charles Newland CBE

Professor William Andrew Owens MD FRCS(CTh)

Professor Rosemary Varley

Ruthe Isden

Shan Abdullah

Dame Caroline Swift

Matthew Thorogood – appointed 1 January 2025

Professor Jill Manthorpe CBE MA PhD (Hon) FAcSS – appointed 1
January 2025

Senior Management Team	Deborah Jack - Joint Chief Executive Katy Singh - Joint Chief Executive Suzanne Lluch - Finance Director Ian Silver - Director of Health & Wellbeing – resigned 26 June 2025
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Medical Advisers	Dr Susan Brennan MBChB MRCP Dr Helen Smith MBChB MRCP Dr Tim Fenn MB BS
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Investment Managers	BlackRock 12 Throgmorton Avenue London EC2N 2DL	
	Schroders Investment Management Limited 1 London Wall Place London Wall London EC2Y 5AU	
	Legal & General Investment Management One Coleman Street London EC2R 5AA	
Investment Consultants	Hymans Robertson 45 Church Street Birmingham B3 2RT	
Solicitors	Withers 20 Old Bailey London EC4M 7AN	HCR Legal LLP Shakespeare House 42 Newmarket Road Cambridge CB5 8EP
Actuaries	Hymans Robertson 20 Waterloo Street Glasgow G2 6DB	
Bankers	Lloyds Bank 39 Threadneedle Street London EC2R 8AU	
Independent auditors	Saffery LLP Westpoint Peterborough Business Park Lynchwood Peterborough PE2 6FZ	

Annual Report

Objectives and activities

The Thalidomide Trust (“the Trust”) was established to provide ‘relief and assistance’ to individuals with disabilities caused by their mothers taking, during pregnancy, a preparation distributed by The Distillers Company (Biochemicals) Limited in the United Kingdom containing the drug known as thalidomide in the late 1950s and early 1960s.

Our Aims

All our beneficiaries are now in their 60s and most are feeling the impact of using their bodies for many years in ways for which they were never designed. In addition, as they get older, they are experiencing a wide range of age-related health problems that are exacerbated by their original thalidomide damage. This seriously impacts their quality of life and their ability to remain fully independent. A small number have experienced a cognitive decline alongside their deteriorating physical health. Many have very complex care needs.

The Trust meets the increasingly complex needs of the beneficiary community through the provision of financial support – in the form of annual grant payments – and a range of information, advice and advocacy services. To underpin this, we gather evidence on the needs and experience of our beneficiaries and undertake more detailed research on topics that are of greatest relevance to them in order to fill evidence gaps or deepen our understanding.

The Trust has a Vision and five Strategic Goals which were jointly developed – and reviewed and updated in 2022 – by the Trustees, staff, and beneficiary representatives:

Our Vision is that each and every beneficiary of the Trust has access to the resources and support they need to live their best life for the longest time.

Our five strategic goals are.....

- GOAL 1:** To ensure the Trust’s income is secure, financial risk is effectively managed and adequate funding is available to meet the increasing needs of beneficiaries as they age.
- GOAL 2:** To apply the Trust’s resources strategically, effectively and equitably (in order to achieve our vision).
- GOAL 3:** To ensure that all beneficiaries have access to the best possible information, advice, advocacy, services and support – both within and outside the Trust – as they age and their physical and mental health needs increase.
- GOAL 4:** To ensure effective (two-way) sharing of knowledge and learning for the benefit of the beneficiary community and for wider public benefit.
- GOAL 5:** To ensure that the individual beneficiary’s needs remain paramount, even when third parties (families, carers, representatives) have a role in acting on their behalf.

Public Benefit

Although the Trust is very much focussed on the needs of a small, discrete community of beneficiaries, Trustees have also had regard to the Charity Commission's guidance on public benefit and so we also take steps to deliver a broader societal value by sharing our research and learning with other thalidomide organisations around the world and, where relevant, with the broader disability community.

The Trust is increasingly aware of the benefit of sharing our experience and lessons learned from fifty years of supporting this unique community with other groups of individuals living with disabilities and the organisations that support them now and in the future. To this end, we are working on a 'Legacy Project' to document the key lessons we have learned that we feel will be most valuable to others facing similar challenges.

Structure, Governance and Management

Structure

The Thalidomide Trust was set up in 1973 - originally as the Thalidomide Children's Trust - and is a charitable discretionary Trust registered with the Charity Commission for England and Wales.

With the consent of the Charity Commission, on 29 January 2018 a new company limited by guarantee, The Thalidomide Trust Company (incorporated on 19 January 2018, Company Number 11160424), was appointed as sole Corporate Trustee of the Trust, replacing the individual Trustees. The Corporate Trustee will be referred to in this document as the Trustee.

The Trustees at the date of incorporation became the Directors of the Company. However, although legally Directors, in recognition of the fact that they function as Trustees and operate within the legal frameworks and guidance of the Charity Commission, they continue to be referred to as Trustees. To reflect this, they are referred to as Trustees (as opposed to the Trustee above) throughout this Annual Report.

The subsidiary valiDATE Trust registered in England and Wales, (established in 2019/20 with company number 12144047) ceased trading on 30 June 2024 and its activities (namely the maintenance and development of a diagnostic algorithm to assess the likelihood of Thalidomide Embryopathy in individuals) were transferred to the Thalidomide Trust. The Directors of valiDATE Trust and the Trustees of the Thalidomide Trust subsequently agreed to strike off valiDATE Trust, and the company was formally dissolved on 18 February 2025. However, the diagnostic algorithm continues to be maintained, to be used by the Trust to screen potential new beneficiaries and to be made available to clinicians in other countries, under the auspices of the Thalidomide Trust.

Trustees (formally Directors of the Trustee Company)

The Trust is governed by a small, highly-skilled Board whose members bring a wealth of experience and expertise to the charity including medical, legal, research, governance, health and social care policy, financial management, actuarial and investment.

Trustees are appointed through a structured recruitment process which focusses on the skills required to meet the current and future needs of beneficiaries.

The recruitment process is overseen by the Trust's Chair and there is direct beneficiary involvement in all Trustee appointments.

The Trust has a well-defined and comprehensive programme of induction for new Trustees and all new Trustees are offered a mentor from within the existing Trustee Board.

The Trustees are legally responsible for the overall management and control of the Trust and meet as a full Board at least three times a year. One of these three meetings is an Awayday which enables the Trustees and the Trust's Senior Management Team to spend dedicated time focussing on long-term strategic issues.

The Trust has two key Standing Committees - the Health & Wellbeing Committee and the Finance Committee - which met two and four times respectively during this year. Both Committees are attended by Beneficiary Members, who are selected through an open recruitment process.

There are two additional Committees which met on an ad hoc basis during 2024/25:

- Claims Committee, which considers all evidence and makes recommendations to the Board regarding whether applicants should be accepted as new beneficiaries of the Trust.
- Research Committee, which oversees all research involving the Trust and its beneficiaries and commissions and shapes new research projects.

Beneficiary Engagement

The Trust employs a number of different mechanisms to engage with its beneficiaries and ensure the charity's Trustees hear directly from beneficiaries and have a good understanding of their lived experiences and evolving needs. These include:

- A **Beneficiary Insights Panel**, comprised of 24 beneficiaries who are broadly representative of the community in terms of type of thalidomide damage, gender, geographic location and length of time as a beneficiary. The role of Panel Members is to share their personal views and lived experience with Trustees.
- Periodic **Trustee Webinars** provide an opportunity for two-way communication between Trustees and beneficiaries.
- **Beneficiary Focus Groups** on different topics or with different groups within the beneficiary community to enable Trustees to better understand their specific needs.
- **Task & Finish Groups** made up of beneficiaries and staff to undertake specific projects.
- **Beneficiary Members on Committees** to ensure that there is always a beneficiary perspective included in important discussions.
- **Periodic Beneficiary Surveys and Consultations.**

In the twelve-month period, there were four meetings of the Beneficiary Insights Panel. The topics discussed by the Panel were Social Connectivity outside the home, the Trust Website, Smart & Assistive Technology and Holiday - Challenges and Solutions.

Two Trustee webinars took place providing an opportunity for beneficiaries to interact directly with Trustees. The first provided beneficiaries with an opportunity to meet the new Chair of Trustees together with a new trustee who joined us in 2025, while the second was on the topic of the Diageo Chairs' Review process, scheduled to take place in 2026. Two Beneficiary Focus Groups were held for beneficiaries with a significant hearing impairment that impacts on their ability to communicate with the Trust. One took place in-person, the other online.

Our new approach to beneficiary engagement has encouraged an increased number of beneficiaries to engage with the Trust in different ways. In addition to the formal engagement mechanisms outlined above, we have two ongoing Working Groups with beneficiary members to ensure that we are keeping on top of developments in areas that are important to beneficiaries

and providing the right sort of support (including peer support). The first focusses on vehicles and vehicle adaptations and the second on SMART and Assistive Technology.

We undertook the third of our periodic Beneficiary Feedback Surveys (BFS) in 2025 and achieved a response rate of 61.5%, with the beneficiaries completing the survey being broadly representative of the whole beneficiary community in terms of their gender, geographic location and type of thalidomide damage. The survey results indicated that beneficiaries are supportive of the activities we have introduced as part of our new approach to Beneficiary Engagement - 81% of respondents agree that the Trust makes an effort to listen to the views of beneficiaries and 85% said they know how to raise their concerns with the Trust, if they have any.

Staff Team

During 2024/25, the day to day running of the Trust was delegated to the joint Chief Executives, Deborah Jack and Katy Singh (formerly Sagoe), supported by a small, dedicated and skilled staff team.

The majority of the staff team are focussed on directly supporting beneficiaries in relation to their health and wellbeing in order to maximise their independence and quality of life.

Remuneration Policy

The Trustees are responsible for the Trust's remuneration policy as well as agreeing annual pay increases for the staff team. Trustees take account of market conditions and the pay practice of other comparable charities and employers in the geographic area.

Volunteers

Many beneficiaries generously volunteer their time and expertise to support the Trust and, through it, the broader beneficiary community.

In the last 12 months over 60 beneficiaries volunteered their time across a broad range of roles, including offering peer support, taking part in working groups, attending Trust committee meetings and meetings with the UK Health (and Social Care) Departments. Beneficiary volunteers are playing a key role in developing resources, including the Future Planning Resource and advice on preparing for Orthopaedic Surgery, and in contributing their time to assist in co-producing research.

Number and Profile of Beneficiaries

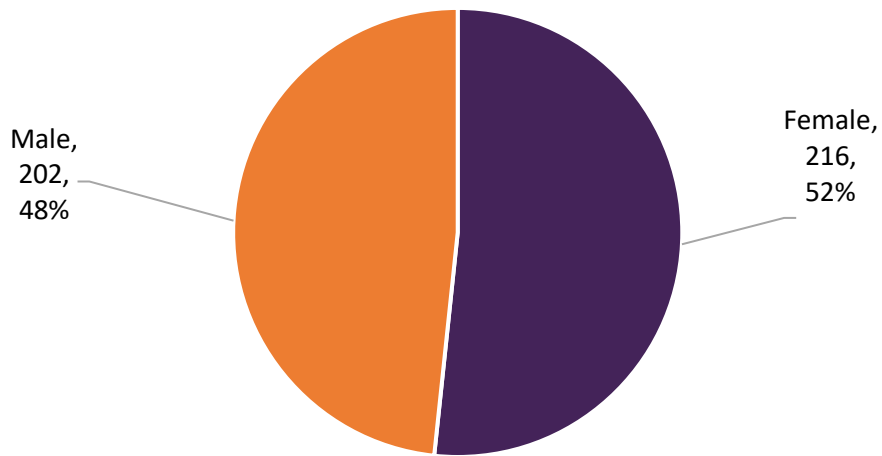
The Trust has responsibility for assessing new applications to become beneficiaries of the Trust and has established a robust procedure for assessing new applications, drawing on international evidence and utilising the diagnostic algorithm, valiDATE, which was one of the key outputs of the WHO conference on Thalidomide Embryopathy held in early 2014.

During the year, the Trust received 45 completed applications from individuals who thought they may be entitled to become beneficiaries. One individual was accepted as a beneficiary in the twelve-month reporting period.

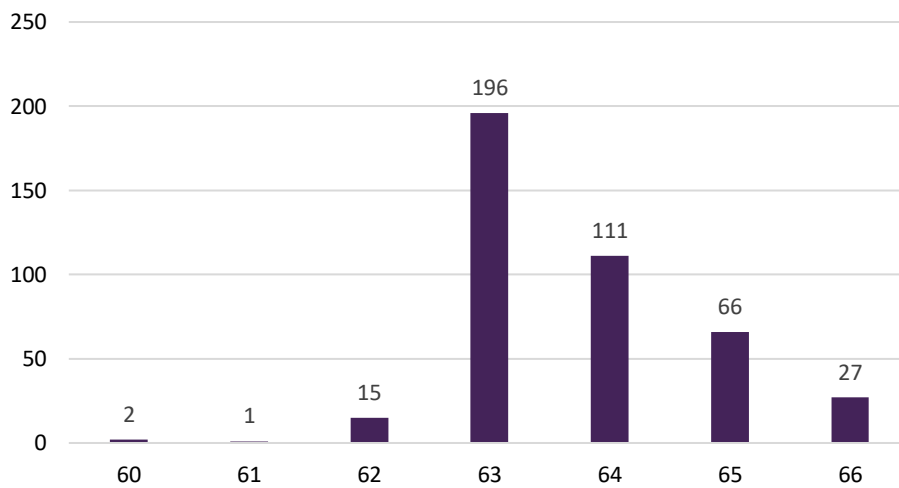
It is with regret that the Trustees report the deaths of nine beneficiaries during the year.

At 30 September 2025 there were 418 beneficiaries (2024: 427). The charts below provide a breakdown of beneficiaries by gender, age and country of residence as at 30 September 2025.

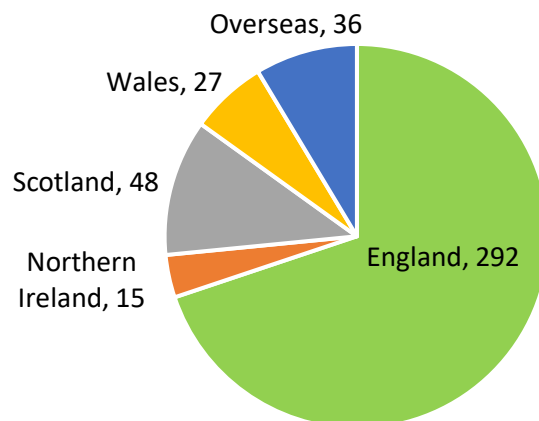
Gender of Beneficiaries



Age of Beneficiaries



Country of Residence



Risk Management

A key role of Trustees is to identify and manage risk and they discharge this duty by means of a Risk Register. The full Risk Register is reviewed by Trustees annually and the most significant risks are reviewed by the Finance Committee on a quarterly basis. Trustees have satisfied themselves that adequate systems and procedures are in place to manage all the identified risks.

As a result of their sustained and proactive approach to risk management, there is only one risk identified as high and that relates to concerns that the pressure on social care services mean that beneficiaries are unable to meet their care and support needs, which are increasing as they age, due to the rising costs of and demand for care and support, reduced funding at local authority level, and geographical pressures and availability of care workers.

In terms of ongoing risk management, we continued our focus on IT security over the year by further strengthening our cybersecurity defences. We moved to a next generation antivirus (NGAV) with 24/7/365 system monitoring by a specialist cybersecurity team, the combination of which provides an advanced level of threat protection. We obtained the UK government-backed Cyber Essentials certification, demonstrating our commitment to protecting our systems and data. As part of our continued vigilance around data protection, we introduced an AI Policy that provides clear guidance on the appropriate use of Generative AI within the Trust.

The Trustees treat safeguarding of our beneficiaries as an important priority, and we have a comprehensive safeguarding policy in place. Sadly, during the 12-month reporting period, safeguarding concerns involving family members or carers were identified in thirteen cases and reported to external bodies (Local Authority Safeguarding leads and/or the Police) in accordance with our Policy.

Achievements and Performance

We continue to gather robust data on our beneficiaries' evolving needs through our structured programme of face-to-face Holistic Needs Assessments and this evidence informs the development of our own services and support and also our discussions with funders. Following the completion of the work undertaken by the Task & Finish Group, a new structured approach to ensuring we understand the needs of overseas beneficiaries, and can provide appropriate support, was piloted successfully and will be introduced for all beneficiaries living outside the UK from 2026.

We continue to provide a wide range of ongoing support to our beneficiaries, tailored to meet their individual needs and, now that they are all in their 60s and experiencing the usual health issues associated with ageing, their needs are becoming increasingly complex and multi-layered.

Over the 12-month period, 269 individual beneficiaries (over 65% of the beneficiary community) had contact with our Health & Wellbeing Team, many on multiple occasions. This compares to 280 beneficiaries in the previous 12-month reporting period.

The most common issues that beneficiaries require support with are health issues – including access to NHS services - mental health/emotional wellbeing, benefits, care and carers, and home adaptations – these issues continue to account for the majority of all contacts with the Health & Wellbeing Team.

In addition to providing significant day-to-day support, at the start of the year we identified a number of ambitious goals for 2024/25.

These are set out on the next page together with an overview of the progress made over the last 12 months:

We said we would...	We...
...complete an evaluation of our Beneficiary Insights Panel	... commissioned an independent evaluation of the panel which identified that the majority of participants valued the Panel as an effective mechanism for engagement. Trustees also felt confident in the insight it gave them. The evaluation suggested a number of small improvements to be addressed in 2026
...conduct our third Beneficiary Feedback Survey	... circulated a feedback survey to all beneficiaries in January 2025, shared the results with our Trustees in April and wrote to all beneficiaries in July with a summary of the findings and told them what action we would be taking in response to these
... implement the outstanding actions from our Independent Governance Review	... agreed an approach to reviewing Board effectiveness and undertook the first review in June 2025. This will be repeated annually.
...commission research into beneficiaries' experiences of inpatient hospital care and into beneficiaries' long-term housing needs and the barriers to them making necessary changes	.. completed the hospital research with Revealing Reality, a leading social policy organisation and will be developing additional advice and support for beneficiaries in 2026. Successfully commissioned Manchester School of Architecture to undertake housing research and this will be completed in 2026
...prepare for Round 4 of Holistic Needs Assessments (HNAs)	 undertook a comprehensive review of the data gathered at HNAs, with beneficiary input, and made some important changes to reflect beneficiaries' evolving needs
...complete and launch a new resource to support beneficiaries with the recruitment and employment of Personal Assistants (PA)	... are close to finalising the new resource, which will be made available in early 2026.

Over the last 12 months, we also:

- Completed our Pain Management research in partnership with Nottingham University Pain Management Centre and developed a proposal for a bespoke holistic pain pathway for beneficiaries.
- Held a Beneficiary Open Day at our office in St Neots and two Local Events for beneficiaries, in Winchester and in Northern Ireland
- Recruited new Beneficiary Members to Health & Wellbeing Committee and Research Committee.

Plans for the Future

In the next 12 months, the Trustees and staff will continue to work together to implement our jointly owned Strategic Plan. Our plans include:

- Building on and embedding the success of beneficiary engagement - including recruiting to our second Beneficiary Insights Panel, as well as to a Task & Finish Group to provide beneficiary input into preparing for the quadrennial Diageo Chairs' Review
- Producing a Future Planning resource pack for beneficiaries to support them to have important conversations about their future wishes and start to plan for their future health and support needs.
- Piloting our new Pain Management Pathway with an initial cohort of beneficiaries and ensuring this is rigorously evaluated by a team from Nottingham University before we consider a wider roll out.
- Completing the research into beneficiaries' long-term housing needs and the barriers to making necessary changes, in order that we can understand what support is required from the Trust to ensure beneficiaries can access their "forever homes".
- Holding our first Future Care Matters (virtual) Event to provide information, support and advice to beneficiaries to understand all aspects of care and support provision, access and funding.
- Launching our new Personal Assistant (PA) Pack to support beneficiaries with the recruitment and employment of Personal Assistants.

Financial Review

The Trust has an investment portfolio of £155m which, combined with annual donations from Diageo, funds the Annual Grants payable to its beneficiaries.

The Trust received donations from Diageo plc totalling £13.5m (2024: £12.4m). Health Grant funding from the four Health (and Social Care) Departments of the United Kingdom totalled £10.5m (2024: £13.3m). As Health Grant funding is provided for specific, agreed health and wellbeing purposes, these are accounted for by the Trust as funds restricted for these purposes. In 2025, the Department of Health & Social Care in England deducted £2.7m from its annual funding corresponding to the balance of funds held for, but not yet required by, the group of beneficiaries who lack decision making capacity (BWLCs) residing in England at the end of the ten-year agreement which ran from 2013 to 2023. In recognition of the fact that this group has complex needs that will increase significantly over time, the Department of Health & Social Care agreed to ringfence these monies to meet their future needs.

During the year the Trust allocated grants totalling £34.9m (2024: £36.4m) to its beneficiaries.

The Trust is committed to managing its resources effectively and achieving value for money. It operates a robust budget management system which involves regular review of activity and expenditure by budget holders, oversight by the Management Team and regular reporting of variances to the Trust's Finance Committee. The Trust does not actively fundraise and 100% of its resources are utilised for charitable purposes, including charity governance. During 2024/25, 93% of outgoing resources were in the form of grants to our beneficiaries. Of the remaining 7% of expenditure, 60% was spent on providing health and wellbeing support and financial guidance directly to our beneficiaries by our staff and volunteers. The balance of resources was utilised to administer beneficiary grants, assess applications from potential new beneficiaries, manage the investment portfolio, and ensure effective governance of the Trust.

Investment Objectives

The principal objective of the investment policy is to generate sufficient income and capital return to enable the Trustees to pay Annual Grants for the entire lives of the beneficiaries.

The environmental, social and governance (ESG) nature of Trust investments has been considered at length by the Trustees. The Trustees believe that ESG-related risks, including climate change risks, are financially material and an important component of investment risk. The Trustees believe that organisations that soundly manage ESG-related risks are more likely to be financially sustainable over time, and therefore deliver better long-term risk-adjusted returns. Trustees currently hold £43m of funds in an ESG fund with Legal & General Investment Management (LGIM).

As all the Trust investments are held within pooled funds, the decisions regarding the selection of investments are entrusted to the investment managers, who each act within agreed guidelines. Trustees regularly ask investment managers to explain how ESG factors are incorporated into their decisions regarding the selection of investments.

In line with the Deed of Covenant with Diageo, the Trustees have adopted an investment policy which will reduce the investment risk of the portfolio over the lifetime of the Trust. Since 2023, in line with the strategy, Trustees began the process of de-risking the portfolio with the long-term intention of achieving a low-risk portfolio by 2037. The low-risk portfolio is defined as a mixture of bonds, cash, swaps and other financial instruments with up to 10% in return-seeking assets, designed to provide the anticipated future payments from the Trust with a significant degree of

certainty. The de-risking carried out this year involved disinvesting £9m from equity funds (held with Schroders and BlackRock) and moving £3m into fixed income funds (held with BlackRock), with the balance serving day-to-day cash needs.

The current benchmark against which performance will be measured is represented by a portfolio comprising of 61.25% global equities and 38.75% bonds.

Investment Strategy and Performance

The investment strategy is currently implemented through a combination of investments and managers as set out in the table below, together with the ranges within which the policy is managed, in line with the Statement of Investment Principles dated September 2023.

Portfolio	Manager	Central Allocation (% of Assets)	Target Ranges (% of Assets)
Active Global Equities	Schroders	22	15-35
Passive Global Equities	BlackRock and LGIM	41	35-55
Bond Portfolios	BlackRock	36	20-40
Cash	Within above portfolios	1	0-20

Cash deposits are held with a variety of banks and investment managers.

The total annual return on the Trust's investments for the year was 11.2% (2024: 17.8%), which compares to a benchmark of 11.3%.

Over the last three years the average rate of return has been 13.7% pa, which compares to a benchmark of 12.1% pa.

Significant Investments

At the year end, the following investments represented 5% or more of the total market value of investments:

	£000s	%
Legal and General Future World ESG Fund	43,051	28
BlackRock Global Corporate ESG Bond Fund	26,851	17
Schroders Global Recovery Fund	25,917	17
BlackRock Overseas Government Bond Fund	25,388	16
BlackRock North America Fund	14,496	9
Schroders Charity Equity Fund	8,275	5

Derivative Instruments

The Trustees have authorised Schroders to use financial contracts, known as derivatives, to help manage investment portfolio risk. However, the Trust's funds with Schroders are currently held in funds with no direct derivative exposure.

At the year end the open derivatives position was a net liability of £0 (note 9) (2024: £0).

Diageo Covenant

A Deed of Covenant is in place, signed by the Trustees and Diageo plc (successor to The Distillers Company), which sets out Diageo's commitment to long-term support for Thalidomide Trust beneficiaries and to underwrite the investment policy of the Trust. The Covenant enables the Thalidomide Trust both to maintain the programme of Annual Grants to its beneficiaries and deliver ongoing support in response to their evolving and growing health and wellbeing needs.

The Deed of Covenant is reviewed by the Trustees and Diageo periodically. During the latest of these discussions in 2023, Diageo agreed an increased level of support which included an additional lump sum grant payment to beneficiaries. These funds were taken from the Trust's existing investment portfolio, as agreed with Diageo. Diageo also agreed additional funding to meet beneficiaries' specific health and wellbeing needs that the Trust was able to evidence from the Holistic Needs Assessments carried out over the preceding six years. Diageo also agreed to make additional financial contributions, if required, to the Trust beyond 2037 which was the date that annual payments were previously expected to cease. In January 2024, an updated Deed of Covenant was signed which reflected this increased support.

Government Health Grants

In addition to the assets held by the Trust and the income from Diageo, the UK government supports the Trust by way of Health Grant funding agreements in place with the four UK Health (and Social Care) Departments since 2009. This money has helped beneficiaries to respond to their growing needs as they age – in order to maximise their independence and quality of life, minimise further deterioration and improve their overall health and wellbeing. In March 2021, the Chancellor, Rishi Sunak, announced a commitment to lifetime funding of the Health Grant to beneficiaries living in England and during 2022 both Wales and Scotland announced the same commitment. In 2023, new Health Grant agreements were signed by the Health (and Social Care) Departments in England, Scotland and Wales which re-stated their commitment to lifetime funding, set out the level of funding for the period from 2023 to 2027 and committed to four-yearly funding reviews. In 2024, the Northern Ireland government announced the same lifetime commitment and signed a comparable grant agreement for beneficiaries living in Northern Ireland.

Grant Making and Reserves Policy

Beneficiaries receive an Annual Grant, based on their level of disability, from funds that come from Diageo each year in line with the Covenant and the Trust's reserves, including the interest and investment growth accrued.

The Trustees' distribution policy continues to provide individual Annual Grants to beneficiaries for the whole of their lives. The Trustees have to set a policy which will ensure reserves are not depleted whilst beneficiaries are in need of funding, whilst at the same time aiming to ensure that all assets are utilised by the time of the death of the last beneficiary. The total unrestricted funds at 30 September 2025 stood at £145m (2024: £142m) whereas the Restricted Fund had a balance of £0.6m at the year-end (2024: £0.7m).

Statement of the Corporate Trustee's Responsibilities

The Trustee is responsible for preparing the Trustee's Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England and Wales requires the Trustee to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and their application for that period.

In preparing these financial statements, the Trustee is required to:

- select suitable accounting policies and then apply them consistently
- observe the methods and principles in the Charities SORP (Statement of Recommended Practice)
- make judgments and estimates that are reasonable and prudent
- state whether applicable accounting standards, comprising FRS 102, have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis¹ unless it is inappropriate to presume that the charity will continue in business.

The Trustee is responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable it to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. The Trustee is also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustee is responsible for the maintenance and integrity of the charity and financial information included on the charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Signed on behalf of the Corporate Trustee:

David Body
Chair of the Board of the Thalidomide Trust Company
28 January 2026

¹ The going concern basis means that the charity has the resources to continue in operations for a minimum of 12 months from the date of signing these financial statements

Independent auditors' report to the Trustee of The Thalidomide Trust

Report on the audit of the financial statements

Opinion

We have audited the financial statements of The Thalidomide Trust for the year ended 30 September 2025 which comprise the Statement of Financial Activities, Balance Sheet, Cash Flow Statement and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102, the Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 30 September 2025 and of its incoming resources and application of resources for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information; we are required to report that fact.

We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 require us to report to you if, in our opinion:

- the information given in the Trustees' Annual Report is inconsistent in any material respect with the financial statements; or
- the charity has not kept sufficient accounting records; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the Trustees' Responsibilities Statement set out on pages 15 and 16, the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Auditors' responsibilities for the audit of the financial statements

We have been appointed as auditors under the Charities Act 2011 and report in accordance with regulations made under that Act.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditors' report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The specific procedures for this engagement and the extent to which these are capable of detecting irregularities, including fraud are detailed below.

Identifying and assessing risks related to irregularities:

We assessed the susceptibility of the charity's financial statements to material misstatement and how fraud might occur, including through discussions with the trustees, discussions within our audit team planning meeting, updating our record of internal controls and ensuring these controls operated as intended. We evaluated possible incentives and opportunities for fraudulent manipulation of the financial statements. We identified laws and regulations that are of significance in the context of the charity by discussions with trustees and updating our understanding of the sector in which the charity operates.

Laws and regulations of direct significance in the context of the charity include the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008 and guidance issued by the Charity Commission for England and Wales.

Audit response to risks identified:

We considered the extent of compliance with these laws and regulations as part of our audit procedures on the related financial statement items including a review of financial statement disclosures. We reviewed the charity's records of breaches of laws and regulations, minutes of meetings and correspondence with relevant authorities to identify potential material misstatements arising. We discussed the charity's policies and procedures for compliance with laws and regulations with members of management responsible for compliance.

During the planning meeting with the audit team, the engagement partner drew attention to the key areas which might involve non-compliance with laws and regulations or fraud. We enquired of management whether they were aware of any instances of non-compliance with laws and regulations or knowledge of any actual, suspected or alleged fraud. We addressed the risk of fraud through management override of controls by testing the appropriateness of journal entries and identifying any significant transactions that were unusual or outside the normal course of business. We assessed whether judgements made in making accounting estimates gave rise to a possible indication of management bias. At the completion stage of the audit, the engagement partner's review included ensuring that the team had approached their work with appropriate professional scepticism and thus the capacity to identify non-compliance with laws and regulations and fraud.

There are inherent limitations in the audit procedures described above and the further removed non-compliance with laws and regulations is from the events and transactions reflected in the financial statements, the less likely we would become aware of it. Also, the risk of not detecting a material misstatement due to fraud is higher than the risk of not detecting one resulting from error, as fraud may involve deliberate concealment by, for example, forgery or intentional misrepresentations, or through collusion.

A further description of our responsibilities is available on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the trustees as a body, for our audit work, for this report, or for the opinions we have formed.

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Saffery LLP

Westpoint
Peterborough Business Park
Lynch Wood
Peterborough
PE2 6FZ

Statutory Auditors

Date:

Saffery LLP is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006

Statement of financial activities for the year ended 30 September 2025

	Note	Unrestricted funds £000s	Restricted funds £000s	Total funds 2025 £000s	Total funds 2024 £000s
Income from:					
Diageo donations	3	13,462	-	13,462	12,373
Health Department grants	5	-	10,545	10,545	13,274
Investment income	2	4,291	243	4,534	4,483
Other income		78	-	78	34
Total		17,831	10,788	28,619	30,164
Expenditure on:					
Raising funds (investment management)	6	(488)	-	(488)	(312)
Charitable activities	6	(26,759)	(10,890)	(37,649)	(39,140)
Total		(27,247)	(10,890)	(38,137)	(39,452)
Net gains/(losses) on investments	9	12,463	-	12,463	18,944
Net income (expenditure)		3,047	(102)	2,945	9,656
Reconciliation of funds					
Fund balances brought forward at 1 October 2024/2023	11	141,736	720	142,456	132,800
Fund balances carried forward at 30 September 2025/2024	11	144,783	618	145,401	142,456

All activities are continuing. All gains and losses recognised in the year are included in the Statement of Financial Activities.

Balance Sheet as at 30 September 2025

		Total funds 30/09/2025 £000s	Total funds 30/09/2024 £000s
	Note		
Fixed assets			
Tangible assets	8	367	402
Investments	9	155,314	154,909
		155,681	155,311
Current assets			
Debtors and prepayments	15	95	125
Advance of grants	15		
amounts falling due within one year		446	267
amounts falling due after one year		581	765
Cash at bank and in hand		10,686	11,380
		11,808	12,537
Creditors: amounts falling due within one year			
Beneficiary nominee accounts	12	(21,717)	(25,149)
Creditors and accruals	16	(371)	(243)
		(22,088)	(25,392)
Net current assets		(10,280)	(12,855)
Total assets less current liabilities		145,401	142,456
Net assets		145,401	142,456
Trust funds			
General fund	11	142,220	138,733
Beneficiary memorandum accounts	11,12	2,563	3,003
		144,783	141,736
Restricted fund	11	618	720
		145,401	142,456

The financial statements on pages 20 to 40 were approved by the Board on 28 January 2026 and signed on behalf of the Corporate Trustee by:

David Body
Director

Mark Benstead
Director

Cash flow statement for the year ended 30 September 2025

	Note	Total funds 2025 £000s	Total funds 2024 £000s
Cash flows from operating activities:			
<i>Net cash provided by /used in operating activities</i>		<u>(17,279)</u>	<u>(18,035)</u>
Cash flows from investing activities			
Dividends, interest and rents from investments		4,534	4,483
Purchase of tangible fixed assets	8	(7)	-
Proceeds from sale of tangible fixed assets		-	-
Purchase of investments	9	(3,000)	(14,180)
Proceeds from sale of investments	9	15,089	25,303
<i>Net cash provided by /used in investing activities</i>		<u>16,616</u>	<u>15,606</u>
Change in cash and cash equivalents in the reporting period		(663)	(2,429)
Cash and cash equivalents as 1 October 2024		12,745	15,174
Cash and cash equivalents as at 30 September 2025		<u>12,082</u>	<u>12,745</u>
Cash held for investment	9	1,396	1,365
Cash at bank and in hand		10,686	11,380
Cash as at 30 September 2025		<u>12,082</u>	<u>12,745</u>
Reconciliation of income/(expenditure) to net cash (outflow) from operating activities			
<i>Net income for the reporting period as per the statement of financial activities</i>		2,945	9,656
Adjustments for:			
Depreciation & profit on disposals		42	41
(Gains)/losses on investments		(12,463)	(18,944)
Dividends, interest and rents from investments		(4,534)	(4,483)
Increase/(decrease) in creditors due within one year		(3,304)	(4,021)
(Increase)/decrease in debtors		35	(284)
<i>Net cash provided by /used in operating activities</i>		<u>(17,279)</u>	<u>(18,035)</u>

Notes to the financial statements for the year ended 30 September 2025

1. Accounting policies

Basis of preparation

The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued in October 2019 and the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2022 and UK Generally Accepted Practice as it applies from 1 January 2019.

The financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following Accounting and Reporting by Charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued in October 2019 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

The Trust, which is an unincorporated discretionary charitable trust, constitutes a public benefit entity as defined by FRS 102. The sole trustee is the Thalidomide Trust Company, which is an incorporated trustee company. The financial statements have been prepared on a going concern basis (that is to say, that the charity has the resources to continue in operations for a minimum of 12 months from the date of signing these financial statements) and accounting policies have been applied consistently.

The undertaking by Diageo plc in their 2024 Deed of Covenant is to make annual donation payments until 2037, with a commitment thereafter to provide further financial contributions, if required, to ensure funding is sufficient to maintain grants for the lifetime of beneficiaries. The Health Grant funding agreements have been formally extended to a lifetime commitment by England, Scotland, Wales and now Northern Ireland. These agreements support the conclusion that the charity is a going concern.

The financial statements are prepared in sterling, which is the functional currency of the Trust, and rounded to the nearest £000. The date for authorisation of the issue of the financial statements was 28 January 2026.

The Thalidomide Trust has taken advantage of the exemption under section 24.13A of the Charities SORP not to prepare consolidated accounts. The financial statements present information about the Trust as an individual entity and not about its group.

Fund accounting

Unrestricted Funds

Unrestricted funds are expendable at the discretion of the Trustees in the furtherance of the objects of the Thalidomide Trust. The Trust's level of reserves is maintained in order to meet the anticipated future grant allocations.

The General Fund and Beneficiary Memorandum Accounts are derived from funds provided by Diageo plc and its predecessors, and investment returns, as defined in note 12.

Notes to the financial statements for the year ended 30 September 2025 (continued)

1. Accounting policies (continued)

Restricted Funds

Restricted income funds are funds whose use is restricted to specific purposes according to the terms on which the funds were received. Where income is received for purposes specified by the donor that income is shown as restricted in the Statement of Financial Activities. Expenditure for the specified purposes is shown as restricted expenditure. Any unexpended balance at the balance sheet date is carried forward as a restricted income fund.

Restricted Funds are derived from the Health (and Social Care) Departments in England, Scotland, Wales and Northern Ireland as detailed in note 5.

Tangible fixed assets

The cost of tangible fixed assets is their purchase cost, together with any incidental costs of acquisition. Depreciation is calculated so as to write off the cost of tangible fixed assets on a straight-line basis over the useful economic lives of the assets concerned.

The principal depreciation rates used are as follows:

Motor vehicles	-	25% per annum
Furniture and equipment	-	20% per annum
Buildings	-	2% per annum
Fixtures and fittings	-	14 % per annum

The Trust has a capitalisation threshold of £2,500.

Tangible fixed assets are written down to their realisable value if it is considered there has been a permanent diminution in their value.

Investments

Unquoted unit trust investments are stated at the market value as established by the administrators of the unit trust. Market value is based upon the buying and selling price of the underlying securities in the relevant market with allowances made for cash, accrued income and costs within the unit trust fund.

Derivatives are initially recognised at transaction value and subsequently measured at their settlement value.

Income from investments

Income from investments is recognised when its receipt is probable and the amount receivable can be measured reliably. Any realised and unrealised gains and losses on revaluation or disposals are combined in the statement of financial activities.

Notes to the financial statements for the year ended 30 September 2025 (continued)

1. Accounting policies (continued)

Other incoming resources

Other income consists mainly of fee income charged to beneficiaries, which is recognised upon the issuance of Advances on future grants to beneficiaries. These Advances are intended to assist with major property, mobility and health related purchases. The fee level is based on the cost to the Trust of making the Advances, which includes a contribution towards the loss of income generated by the Trust's cash and investments as a result of withdrawing the cash to be advanced to the beneficiary. There is also a small level of income from the use by overseas clinicians of the diagnostic algorithm to assess the likelihood of Thalidomide Embryopathy in individuals in other countries.

Diageo donation

The Diageo donation is paid under the terms of a Deed of Covenant dated 9 January 2024 which sets out an undertaking to make annual payments until 2037 and with a commitment thereafter to make further financial contributions, if required, to ensure funding is sufficient to maintain grants for the lifetime of beneficiaries.

The income is recognised when there is evidence of entitlement, receipt is probable and the amount can be measured reliably. For the Diageo donation, this is upon the receipt of the cash each year.

Income from Health (and Social Care) Departments

The income is recognised when there is evidence of entitlement, receipt is probable and the amount can be measured reliably. For the Health (and Social Care) Departments Grants, this is upon the receipt of the cash each year.

Pension arrangements

The Trust operates a defined contribution pension scheme for employees. Contributions are paid into the group scheme, the assets of which are held in an independently administered fund. Contributions are charged to the statement of financial activities as they become payable. The Trust provides no other post-retirement benefits to its employees.

Charitable expenditure

All charitable expenditure is accounted for on an accruals basis and has been classified under the category headings, which aggregate all costs related to each category, as shown in note 6. Where costs cannot be directly attributed to particular headings they have been allocated in proportion to the time spent by staff on work under each heading.

Grant-making

Grants payable are accounted for in full as creditors of the charity when approved by the Trustees. As all grants are made to individuals, The Thalidomide Trust has applied the exemption under section 16.25 of the Charities SORP not to disclose details of the recipients.

Non-financial support costs

Beneficiary support costs comprise the direct costs, including staff, attributable to delivering the Trust's wide range of financial and non-financial support to beneficiaries.

Notes to the financial statements for the year ended 30 September 2025 (continued)

1. Accounting policies (continued)

Governance

Governance costs cover expenditure on maintaining the constitutional and policymaking framework of the Trust and compliance with statutory requirements.

Irrecoverable VAT

Any irrecoverable VAT is charged to the statement of financial activities, or capitalised as part of the cost of the related asset, where appropriate.

Judgements and key sources of estimation uncertainty

Preparation of the financial statements requires management to make significant judgements and estimates. The items in the financial statements where these judgements and estimates have been made include the recognition of incoming donations and grants, and value of the Advances of Grants amounts falling due within, and after, one year.

The value of incoming grants and donations are agreed on an annual basis with both Diageo plc and the four Health (and Social Care) Departments in the UK to reflect the level of support needed for current beneficiaries. Future receipts are not anticipated within the financial statements as there is uncertainty as to the level of the receipts.

Advances of Grants are recovered by the Trust through deductions from future grants allocated to beneficiaries. Where possible, the Trust places a charge on property as security for the Advance and has further reduced the risk of the non-repayment of an Advance through a debit balance insurance policy held by the Trust. Based on these actions, in the judgement of the Trust's management the Advances as at the year-end are fully recoverable.

Notes to the financial statements for the year ended 30 September 2025 (continued)

2. Investment income

	2025 £000s	2024 £000s
Unrestricted		
Global Unit Trusts (Equities)	1,839	2,064
Global Unit Trusts (Fixed Income)	1,841	1,448
UK Charity Funds (Equities)	434	490
Cash Holdings	177	199
	4,291	4,201
Restricted fund		
Cash Holdings	243	282
Total per Statement of Financial Activities	4,534	4,483

3. Diageo plc donation

On 9 January 2024 Diageo plc entered into a Deed of Covenant with the Thalidomide Trust which replaced earlier covenants executed by Guinness plc in 1995 and Diageo plc in 2000, 2005, 2012 and 2018.

Under this Covenant future increases in the Annual Grant paid to beneficiaries will continue to be linked to the Retail Price Index (RPI).

4. Investment management fees

The Investment Managers charge a fee for their services based upon an agreed percentage of the market value of the investments under management and a performance related fee.

The Investment Managers' fees charged for the year amounted to £441,000 (2024: £260,000). The increase is due to the accrual of a performance fee due to Schroders which will become due if their recent outperformance against their benchmark continues to the end of the calendar year.

In addition to the Investment Managers' fees, Trust costs relating to investment management were £47,000 (2024: £52,000). This is made up of £36,000 of investment consultancy services and £11,000 of staff time.

5. Grant-making

Unrestricted Funds: General Grants

The Trustees' grant-making policy has been:

For beneficiaries with capacity to manage their financial affairs

The Trustees maintain a non-interest bearing nominee account for each beneficiary.

An Annual Grant is paid into the nominee account. A beneficiary has absolute entitlement to the balance in his or her nominee account and the balance is recognised as a creditor of the Trust.

5. Grant-making (continued)

Beneficiaries can instruct the Trust to make payments up to the balance in their nominee accounts from which they have entire discretion over the amount and frequency of the payments.

The Annual Grant is calculated with reference to each beneficiary's degree of disability, in accordance with the criteria applicable to distributions set out in the Diageo Deed of Covenant. The Trustees reserve the right to amend the method of calculating the Annual Grant.

In addition to the Annual Grant, the Trustees will consider requests for Major Advances (normally relating to significant one-off costs to meet mobility and housing needs), Short-Term Advances (to enable beneficiaries to make a transition in their housing arrangements where there are complex needs) and Emergency Advances (to meet unanticipated costs in the short term).

Where a Major, Short-Term or Emergency Advance has been made, future Annual Grants will be reduced by the amortisation of the Advance and an agreed annual fee to reflect the costs associated with making the Advance and the reduction in the Trust's investment assets as a result of the Advances. Major Advances will normally result in a reduction to the Annual Grants for a number of years whereas Emergency Advances will normally result in a reduction to the following year's Annual Grant. Short-Term Advances are usually repayable upon the sale of a property, and recoverable from future grants if the sale does not complete within the anticipated timeframe.

In addition, the Trustees have established a small Exceptional Needs Fund which allows beneficiaries with exceptional health and wellbeing needs (which cannot reasonably be met from their existing income) to apply for an additional one-off grant.

For beneficiaries who lack capacity to manage their financial affairs

The Trustees make payments to meet the needs of the beneficiary following discussion with the beneficiary's deputy or attorney officially registered with the appropriate authority (such as the Office of the Public Guardian in the UK) to manage the beneficiary's financial affairs. Once funds have been transferred to the deputy or attorney for the benefit of the beneficiary, control of these funds passes absolutely out of the Trust. However, in line with Trust's policy on beneficiaries who lack capacity, there is a requirement for regular reporting on how these funds are utilised to meet the needs of the beneficiary and professional oversight.

Until such time as beneficiaries who lack capacity have a professional deputy or appointed attorney in place, or where the appointed deputy or attorney has not fully complied with the regular reporting requirements, their Annual Grants are held in Beneficiary Memorandum Accounts as designated funds.

All payments will always remain at the discretion of the Trustees and will be allocated in accordance with the principles set out in the Trust Deed and in line with the Trust's policy on beneficiaries who lack capacity.

Notes to the financial statements for the year ended 30 September 2025 (continued)

5. Grant-making (continued)

Annual Grants	2025	Value of	2024	Value of
	Number of beneficiaries*	grants £000s	Number of beneficiaries*	grants £000s
Beneficiaries with capacity to manage their financial affairs	401	22,683	409	21,878
Beneficiaries who lack capacity to manage their financial affairs	24	1,838	22	1,717
Total of Grants	425	24,521	431	23,595

*At point of allocation.

Restricted Funds: Government Grants

The four UK Health (and Social Care) Departments provide funding for the Health Grants to meet beneficiaries' current and future health and wellbeing needs. In 2023 the governments of England, Scotland and Wales made a commitment to lifetime funding of the Health Grant, and entered into new Health Grant agreements which confirmed this commitment, specified the level of grant funding for the first four-year period and agreed to review the level of funding at the end of the four-year period, based on beneficiary numbers and needs. During the year, the government of Northern Ireland signed a comparable agreement which included the same lifetime commitment of funding and four-year financial reviews.

Health Grant funding is distributed in accordance with the Trust's existing distribution policy. The costs associated with administering the scheme are met from the funding. Details of Health Grant direct and indirect costs are set out in note 6. The level of costs charged has been determined by reference to factors such as the time spent on Health Grant-related work (both administering and monitoring /reporting activities).

Trust staff and Beneficiary Representatives meet with each of the Health (and Social Care) Departments on an ongoing basis. One of the key objectives of these reviews and the related discussions is to actively manage the level of support requested from the four UK Health (and Social Care) Departments and the level and nature of the Health Grant fund expenditure such that there are no long-term deficits, or surpluses, on the restricted Health Grant funds.

Health Grants by Country

	England	Scotland	Wales	N. Ireland	Total
£000s					£000s
Fund balances as at 1 October 2024	438	184	43	55	720
Incoming Health Grants	7,236	1,668	1,083	558	10,545
Health Grants Allocation	(7,150)	(1,621)	(1,072)	(568)	(10,411)
Interest income	157	33	38	15	243
Health Grants - Direct costs	(71)	(18)	(8)	(4)	(101)
Health Grants – Indirect costs	(297)	(49)	(21)	(11)	(378)
Fund balances as at 30 September 2025	313	197	63	45	618

Notes to the financial statements for the year ended 30 September 2025 (continued)

6. Trust costs and net income

		2025			2024		
	Note	Unrestricted £000s	Restricted £000s	Total £000s	Unrestricted £000s	Restricted £000s	Total £000s
Expenditure on raising funds:							
Investment management fees		441	-	441	260	-	260
Support costs (see below)	4	47	-	47	52	-	52
Total Expenditure on raising funds		488	-	488	312	-	312
Charitable activities:							
Grants	5,12	24,521	10,411	34,932	23,595	12,793	36,388
Net decrease in memorandum account balances	11,12	440	-	440	496	-	496
Subtotal		24,961	10,411	35,372	24,091	12,793	36,884
Costs of grant making (see below)		91	24	115	82	23	105
Beneficiary support costs (see below)		1,398	369	1,767	1,319	411	1,730
Support costs (see below)		308	87	395	326	95	421
Total Charitable activities		26,759	10,890	37,649	25,818	13,322	39,140

2025

	Staff and other HR costs	Admin and running costs	Legal, Professional and Audit fees	Beneficiary Engagement	Research & Development	Total Unrestricted	Restricted costs allocation
	£000s	£000s	£000s	£000s	£000s	£000s	£000s
Expenditure on raising funds:							
Investment management	5	6	36	-	-	47	-
Expenditure on charitable activities:							
Costs of grant-making	44	19	28	-	-	91	24
Beneficiary support costs	730	657	4	-	7	1,398	369
Other costs:							
- Governance & admin	171	43	34	29	-	277	
- New claims	15	14	2	-	-	32	
Total other costs	186	57	37	29	-	308	87
Total unrestricted costs	965	739	105	29	7	1,845	
Restricted costs							
Beneficiary support costs - Health Grant recharged	341	111	17	10	-	480	480
Total costs – 2025	1,306	850	122	39	7	2,324	
Total costs - 2024 (see below)	1,274	892	111	26	5	2,308	

Notes to the financial statements for the year ended 30 September 2025 (continued)

6. Trust costs and net income (continued)

Comparative 2024	Staff and other HR costs	Admin and running costs	Legal, Professional and Audit fees	Beneficiary Engagement	Research & Development	Total Unrestricted	Restricted costs allocation
	£000s	£000s	£000s	£000s	£000s	£000s	£000s
Expenditure on raising funds:							
Investment management	8	3	40	-	-	52	-
Expenditure on charitable activities:							
Costs of grant-making	57	18	7	-	-	82	23
Beneficiary support costs	697	613	4	-	5	1,319	411
Other costs:							
- Governance & admin	184	47	43	18	-	292	
- New claims	16	18	-	-	-	34	
Total other costs	200	65	43	18	-	326	95
Total unrestricted costs	962	699	95	18	5	1,779	
Restricted costs							
Beneficiary support costs - Health Grant recharged	312	193	16	8	-	529	529
Total costs – 2024	1,274	892	111	26	5	2,308	

Net income for the year is stated after charging/crediting:

	2025 £000s	2024 £000s
Depreciation	42	41
Audit Fees	34	34
Profit on disposal of fixed assets	-	-

Notes to the financial statements for the year ended 30 September 2025 (continued)

7. Trustee and employee information

The monthly average number of persons employed by the Trust during the year was 22 (2024: 21).

Staff costs (for the above persons)	2025 £000s	2024 £000s
Gross salaries and wages	1,003	930
Social security costs	116	108
Employer pension contributions	98	93
Other employee benefits	33	32
	1,250	1,163

The number of employees whose total emoluments (i.e. salary and taxable benefits) exceeded £60,000 were:

	2025 Number	2024 Number
£60,001 - £70,000	-	1
£70,001 - £80,000	3	-
£80,001 - £90,000	2	2
£110,001 - £120,000	-	-
£120,001 - £130,000	-	1

No remuneration was paid to the Trustees of The Thalidomide Trust Company Ltd (2024: £nil). Travel and subsistence expenses of £8,000 (2024: £7,000) were reimbursed to 7 (2024: 6) Trustees of The Thalidomide Trust Company Ltd during the year.

The total remuneration and benefits received by the Trust's key management personnel was £364,000 (2024: £330,000) for 4 employees (2024: 3).

Notes to the financial statements for the year ended 30 September 2025 (continued)

8. Tangible assets

Tangible assets comprise the following:

	Motor Vehicles	Furniture & equipment	Office Building	Office Refurb	Total
	£000s	£000s	£000s	£000s	£000s
Cost					
At 1 October 2024	26	12	465	159	662
Additions	-	7	-	-	7
Disposals	-	-	-	-	-
At 30 September 2025	26	19	465	159	669
Accumulated depreciation					
At 1 October 2024	15	8	203	34	260
Charged	6	4	9	23	42
Disposals	-	-	-	-	-
At 30 September 2025	21	12	212	57	302
Net book value					
At 30 September 2025	5	7	253	102	367
At 30 September 2024	11	4	262	125	402

All tangible fixed assets are unrestricted.

9. Investments

	2025 £000s	2024 £000s
Unlisted investments		
Equities	98,667	100,895
Fixed Income	55,251	52,649
Cash held for investments (including accrued investment income)	1,396	1,365
Total per Balance Sheet	155,314	154,909

All equities and fixed income are held in Global Unit Trusts.

All investments are held as unrestricted funds.

Notes to the financial statements for the year ended 30 September 2025 (continued)

9. Investments (continued)

The movement on investments in the year was as follows:

	2025 £000s	2024 £000s
Market value b/fwd 1 October 2024	154,909	146,616
Less: Disposal proceeds/ share exchanges	(15,089)	(25,303)
Add: Purchases at cost/share exchanges	3,000	14,180
Realised and unrealised gains/(losses)	12,463	18,944
Increase/(decrease) in cash held for investment (including accrued investment income)	31	472
Market value at 30 September 2025	155,314	154,909
Historical cost at 30 September 2025	115,063	121,523

The Trustees believe that the carrying value of the listed investments is supported by the underlying net assets.

10. Subsidiary

The subsidiary valiDATE Trust ceased trading on 30 June 2024 and its activities (namely the maintenance and development of a diagnostic algorithm to assess the likelihood of Thalidomide Embryopathy in individuals) were transferred to the Thalidomide Trust. The Directors of valiDATE Trust and the Trustees of the Thalidomide Trust subsequently agreed to strike off valiDATE Trust, and the company was formally dissolved on 18 February 2025.

11. Trust Fund including comparatives

	Unrestricted Funds			
	Designated Beneficiary Memorandum Accounts £000s	General Fund £000s	Restricted Fund £000s	Total Trust Funds £000s
Balance as at 1 October 2024	3,003	138,733	720	142,456
Net incoming/(outgoing) resources as per Statement of Financial Activities	-	3,047	(102)	2,945
Adjustment for net increase in beneficiary memorandum accounts (note 12)	(440)	440	-	-
Balance as at 30 September 2025	2,563	142,220	618	145,401
	Note 12		Note 5	

Notes to the financial statements for the year ended 30 September 2025 (continued)

11. Trust Fund including comparatives (continued)

	Unrestricted funds			
	Designated Beneficiary Memorandum Accounts £000s	General Fund £000s	Restricted Fund £000s	Total Trust Funds £000s
Fixed Assets				
Tangible	-	367	-	367
Investments	2,012	153,303	-	155,314
Current Assets				
Debtors and Prepayments	-	95	-	95
Advance of Grants	-	1,027	-	1,027
Cash at Bank and in Hand	551	4,474	5,661	10,686
Creditors: amounts falling due within one year				
Beneficiary nominee accounts	-	(16,674)	(5,043)	(21,717)
Creditors and accrued expenses	-	(371)	-	(371)
Balance as at 30 September 2025	2,563	142,220	618	145,401
	Note 12		Note 5	

	Unrestricted funds			
	Beneficiary Memorandum Accounts £000s	General Fund £000s	Restricted Fund £000s	Total Trust Funds £000s
Comparatives				
Balance as at 1 October 2023	3,499	128,815	486	132,800
Net incoming/(outgoing) resources as per Statement of Financial Activities	-	9,422	234	9,656
Adjustment for net increase in beneficiary memorandum accounts	(496)	496	-	-
Balance as at 30 September 2024	3,003	138,733	720	142,456
	Note 12		Note 5	

Notes to the financial statements for the year ended 30 September 2025 (continued)

11. Trust Fund including comparatives (continued)

Comparatives	Unrestricted funds		Restricted Fund £000s	Total Trust Funds £000s
	Beneficiary memorandum Accounts £000s	General Fund £000s		
Fixed Assets				
Tangible	-	402	-	402
Investments	2,261	152,649	-	154,909
Current Assets				
Debtors and Prepayments	-	125	-	125
Advance of Grants	-	1,032	-	1,032
Cash at Bank and in Hand	742	3,088	7,550	11,380
Creditors: amounts falling due within one year				
Beneficiary nominee accounts	-	(18,319)	(6,830)	(25,149)
Creditors and accrued expenses	-	(243)	-	(243)
Balance as at 30 September 2024	3,003	138,733	720	142,456
	Note 12		Note 5	

12. Beneficiary accounts

Beneficiary Memorandum Accounts are all designated funds and include: accounts for beneficiaries who lack capacity to manage their financial affairs (as detailed at note 5) and lump sum compensation payments allocated to new beneficiaries accepted by the Trust. On the death of a beneficiary, any funds held in Memorandum Accounts revert to the General fund to be used for the benefit of the wider community.

Beneficiary nominee accounts include the Annual Grant funds to which a beneficiary has absolute entitlement and which have not been requested by beneficiaries at the year-end (as detailed in note 5). On the death of a beneficiary, any Annual Grant funds not yet paid out will form part of their estate.

Beneficiary Health Grant accounts include the Health Grant funding made available, but not requested by beneficiaries (as detailed in note 5). On the death of a UK-based beneficiary, any Health Grant funds not yet paid out are deducted from the following year's funding from the respective government.

12. Beneficiary accounts (continued)

	Beneficiary nominee accounts	Beneficiary Health Grant accounts	Total (Nominee and Health Grant accounts) 2025	Beneficiary Memorandum accounts	Total (Memorandum, Nominee and Health Grant accounts) 2025	Total (Memorandum, Nominee and Health Grant accounts) 2024
	£000s	£000s	£000s	£000s	£000s	£000s
As at 1 October 2024:						
Balance Sheet- Beneficiary Nominee Accounts	18,319	6,830	25,149		25,149	29,183
Balance Sheet- Beneficiary Memorandum Accounts				3,003	3,003	3,499
Payments, Allocations & Transfers:						
Annual Grant Allocations	23,391		23,391	1,130	24,521	23,595
Health Grant Allocations		10,411	10,411		10,411	12,793
Payments from Beneficiary Accounts	(25,353)	(12,198)	(37,551)	(1,253)	(38,804)	(40,918)
Transfers between Nominee and Memorandum Accounts	317		317	(317)	-	-
As at 30 September 2025:						
Balance Sheet- Beneficiary Nominee Accounts	16,674	5,043	21,717		21,717	25,149
Balance Sheet- Beneficiary Memorandum Accounts				2,563	2,563	3,003

Note 11

Notes to the financial statements for the year ended 30 September 2025 (continued)

13. Taxation

The Trust is a registered charity, and as such is entitled to certain tax exemptions on income and profits from investments, and surpluses on any trading activities carried on in furtherance of the charity's primary objectives, if these profits and surpluses are applied solely for charitable purposes.

During the current and prior years, all distributions to beneficiaries were paid under the terms of Statutory Instrument 2004 No 1819, which allows distributions from the Trust to be paid free of income tax, and therefore no income tax liability arose.

14. Pension obligations

Defined contribution scheme

Permanent staff are eligible to receive a pension provision equivalent to 10% of gross salary under a defined contribution scheme. During the year employer contributions to this scheme amounted to £98,000 (2024: £93,000). At the end of the year other creditors and accruals included £10,000 (2024: £13,000) payable in respect of employer pension contributions.

15. Debtors

	Total funds 2025 £000s	Total funds 2024 £000s
Advances of Grants		
amounts falling due within one year	446	267
amounts falling due after one year	581	765
Other debtors	3	35
Prepayments and accrued income	92	90
Total	1,122	1,157

As set out in note 5, the Trustees will consider requests for Major Advances, Short-Term and Emergency Advances. The current Advances consist of Major Advances, Short Term Advances and Emergency Advances balances as at 30 September 2025. Major Advances and Emergency Advances are recoverable from future Annual Grant allocations: Emergency Advances are recoverable within one year, and Major Advances are recoverable up to a maximum of ten years. Short Term Advances are repaid upon the sale of a property.

Notes to the financial statements for the year ended 30 September 2025 (continued)

16. Creditors

	Total funds 2025 £000s	Total funds 2024 £000s
Creditors: amounts falling due within one year		
Beneficiary nominee accounts (note 12)	21,717	25,149
Other creditors and accruals	371	243
Total	22,088	25,392

17. Net Debt Disclosure

	At 1 October 2024	Cash-flows	Other non- cash changes	At 30 September 2025
	£	£	£	£
Cash	11,380	(694)	-	10,686
Cash held for investment	1,365	31	-	1,396
Total	12,745	(663)	-	12,082

18. Related Party Transactions

Other than expenses paid to Trustees (see note 7), there were no related party transactions during the year.

There is no parent undertaking. The ultimate controlling party is The Thalidomide Trust Company Ltd.

Notes to the financial statements for the year ended 30 September 2025 (continued)

19. Comparatives for Statement of Financial Activities

Comparatives		Unrestricted Funds £000s	Restricted Funds £000s	Total Funds 2024 £000s
	Note			
Income from:				
Diageo donations	3	12,373	-	12,373
Health Department Grants	5	-	13,274	13,274
Investment income	2	4,201	282	4,483
Other income		34	-	34
Total		<u>16,608</u>	<u>13,556</u>	<u>30,164</u>
Expenditure on:				
Raising funds (solely investment management fees)	6	(312)	-	(312)
Charitable activities	6	(25,818)	(13,322)	(39,140)
Total		<u>(26,130)</u>	<u>(13,322)</u>	<u>(39,452)</u>
Net gains/(losses) on investments	9	18,944	-	18,944
Net income (expenditure)		<u>9,422</u>	<u>234</u>	<u>9,656</u>
Reconciliation of Funds				
Fund balances brought forward At 1 October 2023	11	132,314	486	132,800
Fund balances carried forward at 30 September 2024	11	<u>141,736</u>	<u>720</u>	<u>142,456</u>

THE THALIDOMIDE TRUST

England & Wales - Charity number 266220

Accounts

The Thalidomide Trust

Annual Report and Financial Statements
for the year ended 30 September 2024

Registered Charity Number 266220

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Reference and administrative details

Registered Name	The Thalidomide Trust
Charity number	266220
Registered address	1 Eaton Court Road Eaton Socon St Neots Cambridgeshire PE19 8ER
Corporate Trustee	The Thalidomide Trust Company (incorporated on 19 January 2018 with Company Number 11160424, registered address as above)

Directors of the Corporate

Company

The Directors of The Thalidomide Trust Company during the year and up to the date of approval were:

Mark Spofforth OBE BSc FCA CTA FRSA (Chair of Trustees) – retired
31 December 2024

David Body MA Solicitor of Senior Courts of England & Wales (Chair
of Trustees from 1 January 2025)

Mark Benstead MA MBA

Professor Adrian Charles Newland CBE

Professor William Andrew Owens MD FRCS(CTh)

Professor Rosemary Varley

Ruthe Isden

Shan Abdullah

Dame Caroline Swift

Matthew Thorogood – appointed 1 January 2025

Professor Jill Manthorpe CBE – appointed 1 January 2025

Senior Management Team	Deborah Jack - Joint Chief Executive Katy Sagoe - Joint Chief Executive Suzanne Lluch - Finance Director Ian Silver - Director of Health & Wellbeing
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Medical Advisers	Dr Susan Brennan MBChB MRCP Dr Helen Smith MBChB MRCP Dr Tim Fenn MB BS
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Investment Managers	BlackRock 12 Throgmorton Avenue London EC2N 2DL	
	Schroders Investment Management Limited 1 London Wall Place London Wall London EC2Y 5AU	
	Legal & General Investment Management One Coleman Street London EC2R 5AA	
Investment Consultants	Hymans Robertson 45 Church Street Birmingham B3 2RT	
Solicitors	Withers 20 Old Bailey London EC4M 7AN	HCR Legal LLP Shakespeare House 42 Newmarket Road Cambridge CB5 8EP
Actuaries	Hymans Robertson 20 Waterloo Street Glasgow G2 6DB	
Bankers	Lloyds Bank 39 Threadneedle Street London EC2R 8AU	
Independent auditors	Saffery LLP Westpoint Peterborough Business Park Lynchwood Peterborough PE2 6FZ	

Annual Report

Objectives and activities

The Thalidomide Trust (“the Trust”) was established to provide ‘relief and assistance’ to individuals with disabilities caused by their mothers taking, during pregnancy, a preparation distributed by The Distillers Company (Biochemicals) Limited in the United Kingdom containing the drug known as thalidomide in the late 1950s and early 1960s.

Our Aims

All but two of our beneficiaries are now in their 60s and most are feeling the impact of using their bodies for many years in ways for which they were never designed. In addition, as they get older, they are experiencing a wide range of age-related health problems that are exacerbated by their original thalidomide damage. This seriously impacts on their quality of life and their ability to remain fully independent. A small number have experienced a cognitive decline alongside their deteriorating physical health. Many have very complex care needs.

The Trust meets the increasingly complex needs of the beneficiary community through the provision of financial support – in the form of annual grant payments – and a range of information, advice and advocacy services. To underpin this, we gather evidence on the needs and experience of our beneficiaries and undertake more detailed research on topics that are of greatest relevance to them in order to fill evidence gaps or deepen our understanding.

The Trust has a Vision and five Strategic Goals which were jointly developed – and reviewed and updated in 2022 – by the Trustees, staff, and beneficiary representatives:

Our Vision is that each and every beneficiary of the Trust has access to the resources and support they need to live their best life for the longest time.

Our five strategic goals are.....

- GOAL 1:** To ensure the Trust’s income is secure, financial risk is effectively managed and adequate funding is available to meet the increasing needs of beneficiaries as they age.
- GOAL 2:** To apply the Trust’s resources strategically, effectively and equitably (in order to achieve our vision).
- GOAL 3:** To ensure that all beneficiaries have access to the best possible information, advice, advocacy, services and support – both within and outside the Trust – as they age and their physical and mental health needs increase.
- GOAL 4:** To ensure effective (two-way) sharing of knowledge and learning for the benefit of the beneficiary community and for wider public benefit.
- GOAL 5:** To ensure that the individual beneficiary’s needs remain paramount, even when third parties (families, carers, representatives) have a role in acting on their behalf.

Public Benefit

Although the Trust is very much focussed on the needs of a small, discrete community of beneficiaries, Trustees have also had regard to the Charity Commission's guidance on public benefit and so we also take steps to deliver a broader societal value by sharing our research and learning with other thalidomide organisations around the world and, where relevant, with the broader disability community.

The Trust is increasingly aware of the benefit of sharing our experience and lessons learned from fifty years of supporting this unique community with other groups of individuals living with disabilities and the organisations that support them now and in the future. To this end, we are working on a 'Legacy Project' to document the key lessons we have learned that we feel will be most valuable to others facing similar challenges.

Structure, Governance and Management

Structure

The Thalidomide Trust was set up in 1973 - originally as the Thalidomide Children's Trust - and is a charitable discretionary Trust registered with the Charity Commission for England and Wales.

With the consent of the Charity Commission, on 29 January 2018 a new company limited by guarantee, The Thalidomide Trust Company (incorporated on 19 January 2018, Company Number 11160424), was appointed as sole Corporate Trustee of the Trust, replacing the individual Trustees. The Corporate Trustee will be referred to in this document as the Trustee.

The Trustees at the date of incorporation became the Directors of the Company. However, although legally Directors, in recognition of the fact that they function as Trustees and operate within the legal frameworks and guidance of the Charity Commission, they continue to be referred to as Trustees. To reflect this, they are referred to as Trustees (as opposed to the Trustee above) throughout this Annual Report.

During 2019/20, we set up a new company limited by guarantee as a subsidiary of the Thalidomide Trust, with the consent of the Charity Commission. The valiDATE Trust (registered in England and Wales, with company number 12144047) was established specifically to oversee the maintenance and development of an online diagnostic algorithm to be used by qualified clinicians worldwide to screen individuals using detailed medical data in order to assess the likelihood of Thalidomide Embryopathy (TE) and operated on a not-for-profit basis. However, it became increasingly clear that the level of ongoing use did not justify the additional costs associated with maintaining a separate organisation and it was not financially viable to maintain it in the longer term.

The Directors of the valiDATE Trust and the Thalidomide Trust therefore made the decision to close and strike-off the company in-year. However, the diagnostic algorithm was transferred into the Thalidomide Trust and will continue to be maintained, to be used by the Trust to screen potential new beneficiaries and to be made available to clinicians in other countries, under the auspices of the Thalidomide Trust.

Trustees (formally Directors of the Trustee Company)

The Trust is governed by a small, highly-skilled Board who bring a wealth of experience and expertise to the charity including medical, legal, research, governance, health and social care policy, financial management, actuarial and investment.

Trustees are appointed through a structured recruitment process which focusses on the skills required to meet the current and future needs of beneficiaries.

The recruitment process is overseen by the Trust's Chair and there is direct beneficiary involvement in all Trustee appointments.

The Trust has a well-defined and comprehensive programme of induction for new Trustees and all new Trustees are offered a mentor from within the existing Trustee Board.

The Trustees are legally responsible for the overall management and control of the Trust and meet as a full Board at least three times a year. One of these three meetings is an Awayday which enables the Trustees and the Trust's Senior Management Team to spend dedicated time focussing on long term strategic issues.

The Trust has two key Standing Committees - the Health & Wellbeing Committee and the Finance Committee - which met two and four times respectively during this year. Both Committees are attended by Beneficiary Representatives, who are selected through an open recruitment process.

There are two additional Committees which met on an ad hoc basis during 2023/24:

- Claims Committee, which considers all evidence and makes recommendations to the Board regarding whether applicants should be accepted as new beneficiaries of the Trust.
- Research Committee, which oversees all research involving the Trust and its beneficiaries and commissions and shapes new research projects.

Beneficiary Engagement

The Trust employs a number of different mechanisms to engage with its beneficiaries and ensure the charity's Trustees hear directly from beneficiaries and have a good understanding of their lived experiences and evolving needs. These include:

- A **Beneficiary Insights Panel**, comprised of 24 beneficiaries who are broadly representative of the community in terms of type of thalidomide damage, gender, geographic location and length of time as a beneficiary. The role of Panel Members is to share their personal views and lived experience with Trustees.
- Periodic **Trustee Webinars** to provide an opportunity for two-way communication between Trustees and beneficiaries.
- **Beneficiary Focus Groups** on different topics or with different groups within the beneficiary community to enable Trustees to better understand their specific needs.
- **Task & Finish Groups** made up of beneficiaries and staff to undertake specific projects.
- **Beneficiary Representatives on Committees** to ensure that there is always a beneficiary perspective included in important discussions.
- **Periodic Beneficiary Surveys and Consultations.**

In the twelve-month period, there were two meetings of the Beneficiary Insights Panel. The topics for discussion were selected by Panel Members and the first focussed on 'Care' and the second on 'End of Life'.

There were also two Trustee Webinars providing an opportunity for beneficiaries to interact directly with Trustees, and two Beneficiary Focus Groups – one on the implications of the move to electric vehicles and the second on the additional challenges faced by beneficiaries with a sight impairment.

We also established a Task & Finish Group this year to explore the best ways to ensure that we understand the needs of overseas beneficiaries and can provide appropriate support to them, in the absence of the structured HNA (Holistic Needs Assessment) programme that has been established for beneficiaries living in the UK.

Our new approach to beneficiary engagement has encouraged an increased number of beneficiaries to engage with the Trust in different ways. In addition to the formal engagement mechanisms outlined above, we have set up two ongoing Working Groups with beneficiary members to ensure that we are keeping on top of developments in areas that are important to beneficiaries and providing the right sort of support (including peer support). The first is focussing on vehicles and vehicle adaptations and the second on SMART and Assistive Technology.

Trustees have found the feedback from beneficiaries really valuable and the feedback from beneficiaries indicates that they find the engagement a positive experience. We have also begun the process of planning our next periodic Beneficiary Feedback Survey which is scheduled to be implemented in January 2025.

Staff Team

During 2023/24, the day to day running of the Trust was delegated to the Executive Director, Deborah Jack, supported by a small, dedicated and skilled staff team.

From 1 October 2024, the Trustees agreed a new job-share arrangement with Deborah Jack and Katy Sagoe taking on the role of Joint Chief Executives.

The majority of the staff team are focussed on directly supporting beneficiaries in relation to their health and wellbeing in order to maximise their independence and quality of life.

Remuneration Policy

The Trustees are responsible for the Trust's remuneration policy as well as agreeing annual pay increases for the staff team. Trustees take account of market conditions and the pay practice of other comparable charities and employers in the geographic area.

Volunteers

A number of beneficiaries generously volunteer their time and expertise to support the Trust and, through it, the broader beneficiary community.

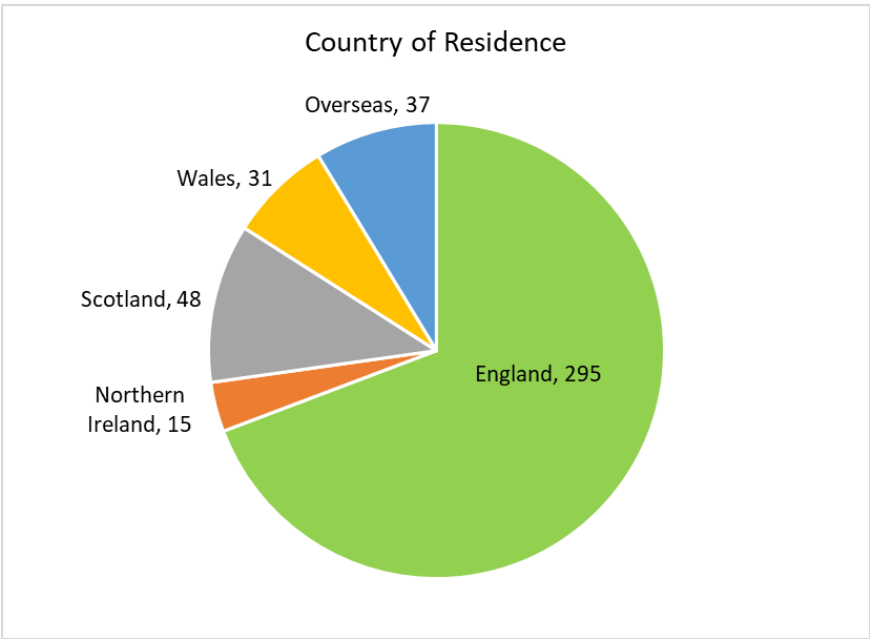
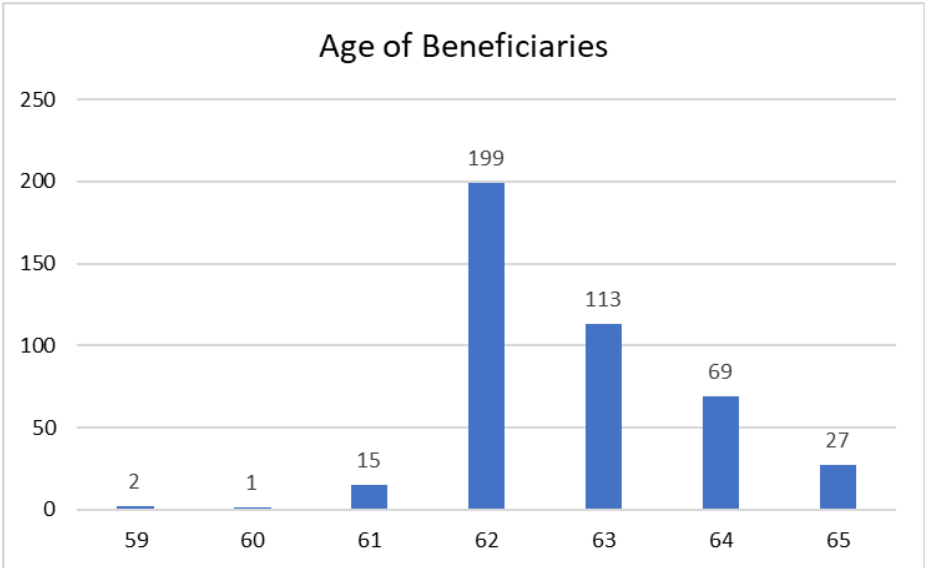
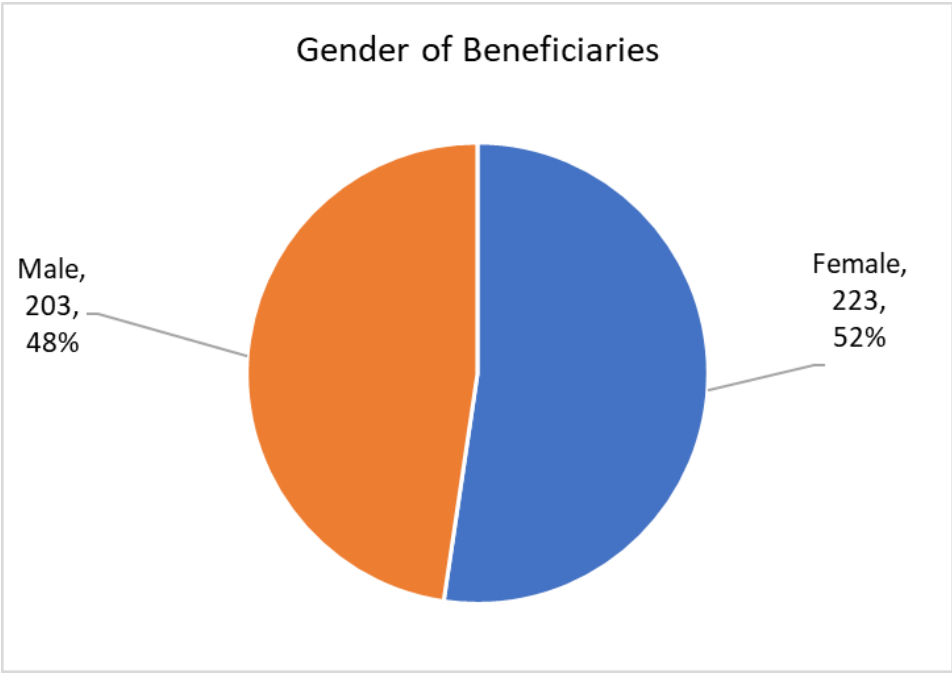
In the last 12 months over 50 beneficiaries volunteered their time in a wide range of roles including: providing practical and/or emotional peer support; hosting virtual beneficiary meetings/events; participating in working groups and as Beneficiary Representatives on Trust Committees; acting as Beneficiary Advisers to our Pain Management Research Project and attending meetings with the four UK Health (and Social Care) Departments.

Number and Profile of Beneficiaries

The Trust has responsibility for assessing new applications to become beneficiaries of the Trust and has established a robust procedure for assessing new applications, drawing on international evidence and utilising the diagnostic algorithm, valiDATE, which was one of the key outputs of the WHO conference on Thalidomide Embryopathy held in early 2014.

During the year, the Trust received 41 completed applications from individuals who thought they may be entitled to become beneficiaries, however, no applicants met the necessary criteria for acceptance in the twelve-month reporting period. It is with regret that the Trustees report the deaths of eight beneficiaries during the year.

At 30 September 2024 there were 426 beneficiaries (2023: 434). The charts below provide a breakdown of beneficiaries by gender, age and country of residence as at 30 September 2024.



Risk Management

A key role of Trustees is to identify and manage risk and they discharge this duty by means of a Risk Register. The full Risk Register is reviewed by Trustees annually and the most significant risks are reviewed by the Finance Committee on a quarterly basis. Trustees have satisfied themselves that adequate systems and procedures are in place to manage all of the identified risks and there are currently no significant areas of concern.

This year, we introduced an enhanced approach to risk management by introducing a new classification of identified risks - as point risks, enduring risks or emerging risks – alongside the level of risk, and this was very helpful in focussing discussions around risk.

In terms of ongoing risk management, we continue to review and strengthen our IT security arrangements by providing regular cyber security awareness training for staff and Trustees and undertaking external penetration testing and phishing simulation campaigns. We continue to maintain a strong focus on data protection and are confident that we are fully GDPR-compliant.

The Trustees treat safeguarding of our beneficiaries as an important priority and we have a comprehensive safeguarding policy in place. Sadly, during the 12-month reporting period, safeguarding concerns involving family members or carers were identified in ten cases and reported to external bodies (Local Authority Safeguarding leads and/or the Police) in accordance with our Policy.

Achievements and Performance

We continue to gather robust data on our beneficiaries' evolving needs through our structured programme of face-to-face Holistic Needs Assessments and this evidence informs the development of our own services and support and also our discussions with funders.

We continue to provide a wide range of ongoing support to our beneficiaries, tailored to meet their individual needs and, now that they are almost all in their 60s and experiencing the usual health issues associated with ageing, their needs are becoming increasingly complex and multi-layered.

Over the 12-month period, 330 individual beneficiaries (over 75% of the beneficiary community) had contact with our Health & Wellbeing Team, many on multiple occasions. This compares to 287 beneficiaries in the previous 12-month reporting period.

The most common issues that beneficiaries require support with are health issues – including access to NHS services - mental health/emotional wellbeing, benefits, care and carers, and home adaptations – these issues account for almost 90% of all contacts with the Health & Wellbeing Team.

In addition to providing significant day-to-day support, at the start of the year we identified a number of ambitious goals for 2023/24.

These are set out on the next page together with an overview of the progress made over the last 12 months:

We said we would...	We...
.... set up a working group on Vehicles and Vehicle Adaptations and identify 'Beneficiary Experts' to ensure that beneficiaries have the information and support they need to make decisions regarding appropriate vehicles and adaptations.	 established the working group, who have done some really valuable work including creating a role description and overseeing the recruitment of seven Beneficiary Advisers (they prefer this title to 'Beneficiary Experts'!)
.... undertake a review of post-66 benefit changes that will affect beneficiaries	... completed the review (working in partnership with Disability Rights UK (DRUK)) and produced a factsheet and web-copy explaining the changes to benefits post statutory-retirement age to beneficiaries.
... implement the outstanding actions from our Independent Governance Review	... implemented the majority of recommendations. The two outstanding areas – implementing delegated decision-making and implementing periodic reviews of Board effectiveness – are scheduled for the first half of 2024/25.
.... develop and embed our new Beneficiary Insights Panel	... arranged induction for Panel Members and provided a high level of ongoing support to enable them to engage fully and participate in discussions
..... undertake a preliminary evaluation of our new Private Treatment Scheme and Specialist Mental Health Network	... undertook an interim review in early 2024, focussing on quantitative data, and have now gathered feedback from beneficiaries in order to complete a more detailed evaluation before the end of the calendar year.
..... develop tailored information for beneficiaries to enable them to understand and access the full range of NHS services that are available post-60	... produced a factsheet outlining availability of services post-65 (which is when most changes to service provision occur) for beneficiaries.

Over the last 12 months, we also:

- Secured a commitment to lifetime Health Grant funding for beneficiaries living in Northern Ireland from their government.
- Implemented the first phase of our Pain Management research in partnership with Nottingham University Pain Management Centre.
- Created a new resource for front-line care staff to help them to better understand, and more effectively meet, the needs of beneficiaries.

- Held a Beneficiary Open Day at our office in St Neots and two Local Events for beneficiaries – one in Queensferry, Scotland, and the other in Birmingham.
- Produced a wealth of information for beneficiaries on cardio-vascular risk and worked with partner organisations across the UK to assist beneficiaries in accessing cardiac CT scans to enable them to assess their cardiovascular risk when they are unable to have reliable blood-pressure readings taken.

Plans for the Future

In the next 12 months, the Trustees and staff will continue to work together to implement our new, jointly-owned Strategic Plan. Our plans include:

- Producing a resource pack for beneficiaries to assist them in recruiting and employing Personal Assistants (PA) in an increasingly challenging care market.
- Completing an evaluation of our Beneficiary Insights Panel.
- Undertaking a programme of activities to support beneficiaries in planning for the future.
- Conducting our third Beneficiary Feedback Survey.
- Commissioning two new research projects – one focussing on beneficiaries' long-term housing needs and the barriers to them making necessary changes, and the second on beneficiaries' experiences of inpatient hospital care.
- Reviewing the data we gather at Holistic Needs Assessments (HNAs) and identifying necessary changes to reflect beneficiaries' evolving needs, ahead of our 'Fourth Round' of HNAs, commencing in January 2026.

Financial Review

The Trust has an investment portfolio of £155m which, combined with annual donations from Diageo, fund the Annual Grants payable to its beneficiaries.

During the year the Trust allocated grants totalling £36.4m (2023: £65.8m) to its beneficiaries. The decrease compared to the previous year was due to the payment in 2023 of an additional one-off lump sum, agreed as part of the four-yearly Diageo Chairs' Review. The Trust received donations from Diageo plc totalling £12.4m (2023: £11.7m).

Health Grant funding from the four Health (and Social Care) Departments of the United Kingdom totalled £13.3m (2023: £13.0m). As Health Grant funding is provided for specific, agreed health and wellbeing purposes, these are accounted for by the Trust as funds restricted for these purposes.

The Trust is committed to managing its resources effectively and achieving value for money. It operates a robust budget management system which involves regular review of activity and expenditure by budget holders, oversight by the Management Team and regular reporting of variances to the Trust's Finance Committee. The Trust does not actively fundraise and 100% of its resources are utilised for charitable purposes, including charity governance. During 2023/24, 93% of outgoing resources were in the form of grants to our beneficiaries. Of the remaining 7% of expenditure, three-quarters was spent on providing health and wellbeing support and financial guidance directly to our beneficiaries by our staff and volunteers. The balance of resources was utilised to administer beneficiary grants, assess applications from potential new beneficiaries, manage the investment portfolio, and ensure effective governance of the Trust.

Investment Objectives

The principal objective of the investment policy is to generate sufficient income and capital return to enable the Trustees to pay Annual Grants for the entire lives of the beneficiaries.

The environmental, social and governance (ESG) nature of Trust investments has been considered at length by the Trustees. The Trustees believe that ESG-related risks, including climate change risks, are financially material and an important component of investment risk. The Trustees believe that organisations that soundly manage ESG-related risks are more likely to be financially sustainable over time, and therefore deliver better long-term risk-adjusted returns. Trustees currently hold £37.5m of funds in an ESG fund with Legal & General Investment Management (LGIM).

As all of the Trust investments are held within pooled funds, the decisions regarding the selection of investments is entrusted to the investment managers, who each act within agreed guidelines. Trustees regularly ask investment managers to explain how ESG factors are incorporated into their decisions regarding the selection of investments.

In line with the Deed of Covenant with Diageo, the Trustees have adopted an investment policy which will reduce the investment risk of the portfolio over the lifetime of the Trust. Since 2023, in line with the strategy, Trustees began the process of de-risking the portfolio with the long-term intention of achieving a low-risk portfolio by 2037. The low-risk portfolio is defined as a mixture of bonds, cash, swaps and other financial instruments with up to 10% in return-seeking assets, designed to provide the anticipated future payments from the Trust with a significant degree of certainty. The de-risking carried out this year involved disinvesting in full (£6.4m) from Twentyfour Asset Management as well as moving £10.5m from equities (held by Schroders, BlackRock and Legal & General Investment Management) into the BlackRock fixed income portfolio.

The current benchmark against which performance will be measured is represented by a portfolio comprising of 65% global equities and 35% bonds.

Investment Strategy and Performance

The investment strategy is currently implemented through a combination of investments and managers as set out in the table below, together with the ranges within which the policy is managed, in line with the Statement of Investment Principles dated September 2023.

Portfolio	Manager	Central Allocation (% of Assets)	Target Ranges (% of Assets)
Active Global Equities	Schroders	24	15-35
Passive Global Equities	BlackRock and LGIM	41	35-55
Bond Portfolios	BlackRock	34	20-40
Cash	Within above portfolios	1	0-20

Cash deposits are held with a variety of banks and investment managers.

The total annual return on the Trust's investments for the year was 17.8% (2023: 12.2%) which is higher than the benchmark of 16.0%. This strong performance has been driven by equities held with BlackRock and Legal & General Investment Management.

Over the last three years the average rate of return has been 7.6% pa, which is higher than the benchmark of 7.2% pa.

Significant Investments

At the year end, the following investments represented 5% or more of the total market value of investments:

	£000s	%
Legal and General Future World ESG Fund	37,546	24
Schroders Global Recovery Fund	27,664	18
BlackRock Global Corporate ESG Bond	26,418	17
BlackRock Overseas Government Bond	25,234	16
BlackRock North America Fund	17,648	11
Schroders Charity Equity Fund	9,318	6

Derivative Instruments

The Trustees have authorised Schroders to use financial contracts, known as derivatives, to help manage investment portfolio risk. At the year end the open derivatives position was a net liability of £0 (note 9) (2023: £0).

Diageo Covenant

A Deed of Covenant is in place, signed by the Trustees and Diageo plc (successor to The Distillers Company), which sets out Diageo's commitment to long-term support for Thalidomide Trust beneficiaries and to underwrite the investment policy of the Trust. The Covenant enables the Thalidomide Trust both to maintain the programme of Annual Grants to its beneficiaries and deliver ongoing support in response to their evolving and growing health and wellbeing needs.

The Deed of Covenant is reviewed by the Trustees, beneficiary representatives and Diageo periodically. During the latest of these discussions in 2023, Diageo agreed an increased level of support which included an additional lump sum grant payment to beneficiaries in recognition of their increasing health and wellbeing needs as they get older. These funds were taken from the Trust's existing investment portfolio, as agreed with Diageo. Diageo also agreed additional funding to meet specific health and wellbeing needs that the Trust was able to evidence from the Holistic Needs Assessments carried out over the preceding six years. In January 2024, an updated Deed of Covenant was signed which reflected this increased support.

Government Health Grants

In addition to the assets held by the Trust and the income from Diageo, the UK government supports the Trust by way of Health Grant funding agreements in place with the four UK Health (and Social Care) Departments since 2009. This money has helped beneficiaries to respond to their growing needs as they age – in order to maximise their independence and quality of life, minimise further deterioration and improve their overall health and wellbeing. In March 2021, the Chancellor, Rishi Sunak, announced a commitment to lifetime funding of the Health Grant to beneficiaries living in England and during 2022 both Wales and Scotland announced the same commitment. In 2023, new Health Grant agreements were signed by the Health (and Social Care) Departments in England, Scotland and Wales which cover the period to 2027. In 2024, the Northern Ireland government announced the same lifetime commitment and grant agreement for beneficiaries living in Northern Ireland.

Grant Making and Reserves Policy

Beneficiaries receive an Annual Grant, based on their level of disability, from funds that come from Diageo each year in line with the Covenant and the Trust's reserves, including the interest and investment growth accrued.

The Trustees' distribution policy continues to provide individual Annual Grants to beneficiaries for the whole of their lives. The Trustees have to set a policy which will ensure reserves are not depleted whilst beneficiaries are in need of funding, whilst at the same time aiming to ensure that all assets are utilised by the time of the death of the last beneficiary. The total unrestricted funds at 30 September 2024 stood at £142m (2023: £132m) whereas the Restricted Fund had a balance of £0.7m at the year-end (2023: £0.5m).

Statement of the Corporate Trustee's Responsibilities

The Trustee is responsible for preparing the Trustee's Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England and Wales requires the Trustee to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and their application for that period.

In preparing these financial statements, the Trustee is required to:

- select suitable accounting policies and then apply them consistently
- observe the methods and principles in the Charities SORP (Statement of Recommended Practice)
- make judgments and estimates that are reasonable and prudent
- state whether applicable accounting standards, comprising FRS 102, have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis¹ unless it is inappropriate to presume that the charity will continue in business.

The Trustee is responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable it to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. The Trustee is also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustee is responsible for the maintenance and integrity of the charity and financial information included on the charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Signed on behalf of the Corporate Trustee:

David Body

Chair of the Board of the Thalidomide Trust Company

22 January 2025

¹ The going concern basis means that the charity has the resources to continue in operations for a minimum of 12 months from the date of signing these financial statements

Independent auditors' report to the Trustee of The Thalidomide Trust

Report on the audit of the financial statements

Opinion

We have audited the financial statements of The Thalidomide Trust for the year ended 30 September 2024 which comprise the Statement of Financial Activities, Balance Sheet, Cash Flow Statement and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102, the Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 30 September 2024 and of its incoming resources and application of resources for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information; we are required to report that fact.

We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 require us to report to you if, in our opinion:

- the information given in the Trustees' Annual Report is inconsistent in any material respect with the financial statements; or
- the charity has not kept sufficient accounting records; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the Trustees' Responsibilities Statement set out on pages 15 to 16, the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Auditors' responsibilities for the audit of the financial statements

We have been appointed as auditors under the Charities Act 2011 and report in accordance with regulations made under that Act.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditors' report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The specific procedures for this engagement and the extent to which these are capable of detecting irregularities, including fraud are detailed below.

Identifying and assessing risks related to irregularities:

We assessed the susceptibility of the charity's financial statements to material misstatement and how fraud might occur, including through discussions with the trustees, discussions within our audit team planning meeting, updating our record of internal controls and ensuring these controls operated as intended. We evaluated possible incentives and opportunities for fraudulent manipulation of the financial statements. We identified laws and regulations that are of significance in the context of the charity by discussions with trustees and updating our understanding of the sector in which the charity operates.

Laws and regulations of direct significance in the context of the charity include the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008 and guidance issued by the Charity Commission for England and Wales.

Audit response to risks identified:

We considered the extent of compliance with these laws and regulations as part of our audit procedures on the related financial statement items including a review of financial statement disclosures. We reviewed the charity's records of breaches of laws and regulations, minutes of meetings

and correspondence with relevant authorities to identify potential material misstatements arising. We discussed the charity's policies and procedures for compliance with laws and regulations with members of management responsible for compliance.

During the planning meeting with the audit team, the engagement partner drew attention to the key areas which might involve non-compliance with laws and regulations or fraud. We enquired of management whether they were aware of any instances of non-compliance with laws and regulations or knowledge of any actual, suspected or alleged fraud. We addressed the risk of fraud through management override of controls by testing the appropriateness of journal entries and identifying any significant transactions that were unusual or outside the normal course of business. We assessed whether judgements made in making accounting estimates gave rise to a possible indication of management bias. At the completion stage of the audit, the engagement partner's review included ensuring that the team had approached their work with appropriate professional scepticism and thus the capacity to identify non-compliance with laws and regulations and fraud.

There are inherent limitations in the audit procedures described above and the further removed non-compliance with laws and regulations is from the events and transactions reflected in the financial statements, the less likely we would become aware of it. Also, the risk of not detecting a material misstatement due to fraud is higher than the risk of not detecting one resulting from error, as fraud may involve deliberate concealment by, for example, forgery or intentional misrepresentations, or through collusion.

A further description of our responsibilities is available on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the trustees as a body, for our audit work, for this report, or for the opinions we have formed.

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Saffery LLP

Westpoint
Peterborough Business Park
Lynch Wood
Peterborough
PE2 6FZ

Statutory Auditors

Date:

Saffery LLP is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

Statement of financial activities for the year ended 30 September 2024

	Note	Unrestricted funds £000s	Restricted funds £000s	Total funds 2024 £000s	Total funds 2023 £000s
Income from:					
Diageo donations:	3	12,373	-	12,373	11,666
Health Department grants	5	-	13,274	13,274	13,037
Investment income	2	4,201	282	4,483	5,023
Other income		34	-	34	75
Total		16,608	13,556	30,164	29,801
Expenditure on:					
Raising funds (solely investment management fees)	6	(312)	-	(312)	(316)
Charitable activities	6	(25,818)	(13,322)	(39,140)	(67,768)
Total		(26,130)	(13,322)	(39,452)	(68,084)
Net gains/(losses) on investments	9	18,944	-	18,944	13,273
Net income (expenditure)		9,422	234	9,656	(25,010)
Reconciliation of funds					
Fund balances brought forward at 1 October 2023/2022	11	132,314	486	132,800	157,810
Fund balances carried forward at 30 September 2024/2023	11	141,736	720	142,456	132,800

All activities are continuing. All gains and losses recognised in the year are included in the Statement of Financial Activities.

Balance Sheet as at 30 September 2024

		Total funds 30/09/2024 £000s	Total funds 30/09/2023 £000s
	Note		
Fixed assets			
Tangible assets	8	402	443
Investments	9	154,909	146,616
		155,311	147,059
Current assets			
Debtors and prepayments	15	125	108
Advance of grants	15		
amounts falling due within one year		267	214
amounts falling due after one year		765	551
Cash at bank and in hand		11,380	14,281
		12,537	15,154
Creditors: amounts falling due within one year			
Beneficiary nominee accounts	12	(25,149)	(29,183)
Creditors and accruals	16	(243)	(230)
		(25,392)	(29,413)
Net current assets		(12,855)	(14,259)
Total assets less current liabilities		142,456	132,800
Net assets		142,456	132,800
Trust funds			
General fund	11	138,733	128,815
Beneficiary memorandum accounts	11,12	3,003	3,499
		141,736	132,314
Restricted fund	11	720	486
		142,456	132,800

The financial statements on pages 20 to 40 were approved by the Board on 22 January 2025 and signed on behalf of the Corporate Trustee by:

David Body
Director

Mark Benstead
Director

Cash flow statement for the year ended 30 September 2024

	Note	Total funds 2024 £000s	Total funds 2023 £000s
Cash flows from operating activities:			
<i>Net cash provided by (used in) operating activities</i>		<u>(18,035)</u>	<u>(35,941)</u>
Cash flows from investing activities			
Dividends, interest and rents from investments		4,483	5,023
Purchase of tangible fixed assets	8	-	(159)
Proceeds from sale of tangible fixed assets		-	14
Purchase of investments	9	(14,180)	(37,591)
Proceeds from sale of investments	9	25,303	74,466
<i>Net cash provided by (used in) investing activities</i>		<u>15,606</u>	<u>41,753</u>
Change in cash and cash equivalents in the reporting period		(2,429)	5,812
Cash and cash equivalents as 1 October 2023		15,174	9,362
Cash and cash equivalents as at 30 September 2024		<u>12,745</u>	<u>15,174</u>
Cash held for investment	9	1,365	893
Cash at bank and in hand		11,380	14,281
Cash as at 30 September 2024		<u>12,745</u>	<u>15,174</u>
Reconciliation of income/(expenditure) to net cash (outflow) from operating activities			
<i>Net expenditure for the reporting period as per the statement of financial activities</i>		9,656	(25,010)
Adjustments for:			
Depreciation & profit on disposals		41	26
(Gains)/losses on investments		(18,944)	(13,273)
Dividends, interest and rents from investments		(4,483)	(5,023)
Increase/(decrease) in creditors due within one year		(4,021)	6,480
(Increase)/decrease in debtors		(284)	859
<i>Net cash provided by (used in) operating activities</i>		<u>(18,035)</u>	<u>(35,941)</u>

1. Accounting policies

Basis of preparation

The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued in October 2019 and the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2022 and UK Generally Accepted Practice as it applies from 1 January 2019.

The financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following Accounting and Reporting by Charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued in October 2019 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

The Trust, which is an unincorporated discretionary charitable trust, constitutes a public benefit entity as defined by FRS 102. The sole trustee is the Thalidomide Trust Company, which is an incorporated trustee company. The financial statements have been prepared on a going concern basis (that is to say, that the charity has the resources to continue in operations for a minimum of 12 months from the date of signing these financial statements) and accounting policies have been applied consistently.

The undertaking by Diageo plc in their 2024 Deed of Covenant is to make annual donation payments until 2037, with a commitment thereafter to ensure funding is sufficient to maintain grants for the lifetime of beneficiaries. The Health Grant funding agreements have been formally extended to a lifetime commitment by England, Scotland, Wales and now Northern Ireland. These agreements support the conclusion that the charity is a going concern.

The financial statements are prepared in sterling, which is the functional currency of the Trust, and rounded to the nearest £000. The date for authorisation of the issue of the financial statements was 22 January 2025.

The Thalidomide Trust has taken advantage of the exemption under section 24.13A of the Charities SORP not to prepare consolidated accounts. The financial statements present information about the Trust as an individual entity and not about its group.

Fund accounting

Unrestricted Funds

Unrestricted funds are expendable at the discretion of the Trustees in the furtherance of the objects of the Thalidomide Trust. The Trust's level of reserves is maintained in order to meet the anticipated future grant allocations.

The General Fund and Beneficiary Memorandum Accounts are derived from funds provided by Diageo plc and its predecessors, and investment returns, as defined in note 12.

Notes to the financial statements for the year ended 30 September 2024 (continued)

1. Accounting policies (continued)

Restricted Funds

Restricted income funds are funds whose use is restricted to specific purposes according to the terms on which the funds were received. Where income is received for purposes specified by the donor that income is shown as restricted in the Statement of Financial Activities. Expenditure for the specified purposes is shown as restricted expenditure. Any unexpended balance at the balance sheet date is carried forward as a restricted income fund.

Restricted Funds are derived from the Health (and Social Care) Departments in England, Scotland, Wales and Northern Ireland as detailed in note 5.

Tangible fixed assets

The cost of tangible fixed assets is their purchase cost, together with any incidental costs of acquisition. Depreciation is calculated so as to write off the cost of tangible fixed assets on a straight-line basis over the useful economic lives of the assets concerned.

The principal depreciation rates used are as follows:

Motor vehicles	-	25% per annum
Furniture and equipment	-	20% per annum
Buildings	-	2% per annum
Fixtures and fittings	-	14 % per annum

The Trust has a capitalisation threshold of £2,500.

Tangible fixed assets are written down to their realisable value if it is considered there has been a permanent diminution in their value.

Investments

Unquoted unit trust investments are stated at the market value as established by the administrators of the unit trust. Market value is based upon the buying and selling price of the underlying securities in the relevant market with allowances made for cash, accrued income and costs within the unit trust fund.

Derivatives are initially recognised at transaction value and subsequently measured at their settlement value.

Income from investments

Income from investments is recognised when its receipt is probable and the amount receivable can be measured reliably. Any realised and unrealised gains and losses on revaluation or disposals are combined in the statement of financial activities.

Notes to the financial statements for the year ended 30 September 2024 (continued)

1. Accounting policies (continued)

Other incoming resources

Other income consists of fee income charged to beneficiaries, which is recognised upon the issuance of Advances on future grants to beneficiaries. These Advances are intended to assist with major property, mobility and health related purchases. The fee level is based on the cost to the Trust of making the Advances, which includes a contribution towards the loss of income generated by the Trust's cash and investments as a result of withdrawing the cash to be advanced to the beneficiary.

Diageo donation

The Diageo donation is paid under the terms of a Deed of Covenant dated 9 January 2024 which sets out an undertaking to make annual payments until 2037 and with a commitment thereafter to further financial contributions if required, to ensure funding is sufficient to maintain grants for the lifetime of beneficiaries.

The income is recognised when there is evidence of entitlement, receipt is probable and the amount can be measured reliably. For the Diageo donation, this is upon the receipt of the cash each year.

Income from Health (and Social Care) Departments

The income is recognised when there is evidence of entitlement, receipt is probable and the amount can be measured reliably. For the Health (and Social Care) Departments Grants, this is upon the receipt of the cash each year.

Pension arrangements

The Trust operates a defined contribution pension scheme for employees. Contributions are paid into the group scheme, the assets of which are held in an independently administered fund. Contributions are charged to the statement of financial activities as they become payable. The Trust provides no other post-retirement benefits to its employees.

Charitable expenditure

All charitable expenditure is accounted for on an accruals basis and has been classified under the category headings, which aggregate all costs related to each category, as shown in note 6. Where costs cannot be directly attributed to particular headings they have been allocated in proportion to the time spent by staff on work under each heading.

Grant-making

Grants payable are accounted for in full as creditors of the charity when approved by the Trustees.

Notes to the financial statements for the year ended 30 September 2024 (continued)

1. Accounting policies (continued)

Non-financial support costs

Beneficiary support costs comprise the direct costs, including staff, attributable to delivering the Trust's wide range of financial and non-financial support to beneficiaries.

Governance

Governance costs cover expenditure on maintaining the constitutional and policymaking framework of the Trust and compliance with statutory requirements.

Irrecoverable VAT

Any irrecoverable VAT is charged to the statement of financial activities, or capitalised as part of the cost of the related asset, where appropriate.

Judgements and key sources of estimation uncertainty

Preparation of the financial statements requires management to make significant judgements and estimates. The items in the financial statements where these judgements and estimates have been made include the recognition of incoming donations and grants, and value of the Advances of Grants amounts falling due within, and after, one year.

The value of incoming grants and donations are agreed on an annual basis with both Diageo plc and the four Health (and Social Care) Departments in the UK to reflect the level of support needed for current beneficiaries. Future receipts are not anticipated within the financial statements as there is uncertainty as to the level of the receipts.

Advances of Grants are recovered by the Trust through deductions from future grants allocated to beneficiaries. Where possible, the Trust places a charge on property as security for the Advance and has further reduced the risk of the non-repayment of an Advance through a debit balance insurance policy held by the Trust. Based on these actions, in the judgement of the Trust's management the Advances as at the year-end are fully recoverable.

Notes to the financial statements for the year ended 30 September 2024 (continued)

2. Investment income

	2024 £000s	2023 £000s
Unrestricted		
Global Unit Trusts (Equities)	2,064	2,641
Global Unit Trusts (Fixed Income)	1,448	1,327
UK Charity Funds (Equities)	490	613
Cash Holdings	199	305
	4,201	4,886
Restricted fund		
Cash Holdings	282	137
Total per Statement of Financial Activities	4,483	5,023

3. Diageo plc donation

On 9 January 2024 Diageo plc entered into a Deed of Covenant with the Thalidomide Trust which replaced earlier covenants executed by Guinness plc in 1995 and Diageo plc in 2000, 2005, 2012 and 2018.

Under this Covenant future increases in the Annual Grant paid to beneficiaries will continue to be linked to the Retail Price Index (RPI).

4. Investment management fees

The Investment Managers charge a fee for their services based upon an agreed percentage of the market value of the investments under management and a performance related fee.

The Investment Managers' fees charged for the year amounted to £260,000 (2023: £271,000).

In addition to the Investment Managers' fees, Trust costs relating to investment management were £52,000 (2023: £44,000). This is made up of £40,000 of investment consultancy services and £11,000 of staff time.

5. Grant-making

Unrestricted Funds: General Grants

The Trustees' grant-making policy has been:

For beneficiaries with capacity to manage their financial affairs

The Trustees maintain a non-interest bearing nominee account for each beneficiary.

An Annual Grant is paid into the nominee account. A beneficiary has absolute entitlement to the balance in his or her nominee account and the balance is recognised as a creditor of the Trust.

5. Grant-making (continued)

Beneficiaries can instruct the Trust to make payments up to the balance in their nominee accounts from which they have entire discretion over the amount and frequency of the payments.

The Annual Grant is calculated with reference to the financial position of the Trust and each beneficiary's degree of disability, in accordance with the criteria applicable to distributions set out in the Diageo Deed of Covenant. The Trustees reserve the right to amend the method of calculating the Annual Grant.

In addition to the Annual Grant, the Trustees will consider requests for Major Advances (normally relating to significant one-off costs to meet mobility and housing needs), Short-Term Advances (to enable beneficiaries to make a transition in their housing arrangements where there are complex needs) and Emergency Advances (to meet unanticipated costs in the short term).

Where a Major, Short-Term or Emergency Advance has been made, future Annual Grants will be reduced by the amortisation of the Advance and an agreed annual fee to reflect the costs associated with making the Advance and the reduction in the Trust's investment assets as a result of the Advances. Major Advances will normally result in a reduction to the Annual Grants for a number of years whereas Short-Term and Emergency Advances will normally result in a reduction to the following year's Annual Grant.

In addition, the Trustees have established a small Exceptional Needs Fund which allows beneficiaries with exceptional health and wellbeing needs which cannot reasonably be met from their existing income to apply for an additional one-off grant.

For beneficiaries who lack capacity to manage their financial affairs

The Trustees make payments to meet the needs of the beneficiary following discussion with the beneficiary's deputy or attorney officially registered with the Court of Protection to manage the beneficiary's financial affairs. Once funds have been transferred to the deputy or attorney for the benefit of the beneficiary, control of these funds passes absolutely out of the Trust. However, in line with Trust's policy on beneficiaries who lack capacity, there is a requirement for regular reporting on how these funds are utilised to meet the needs of the beneficiary and professional oversight.

Until such time as beneficiaries who lack capacity have a professional deputy in place, or where the appointed deputy has not fully complied with the regular reporting requirements, their Annual Grants are held in Beneficiary Memorandum Accounts as designated funds.

All payments will always remain at the discretion of the Trustees and will be allocated in accordance with the principles set out in the Trust Deed and in line with the Trust's policy on beneficiaries who lack capacity.

Notes to the financial statements for the year ended 30 September 2024 (continued)

5. Grant-making (continued)

Annual Grants	2024	Value of grants £000s	2023	Value of grants £000s
	Number of beneficiaries*		Number of beneficiaries*	
Beneficiaries with capacity to manage their financial affairs	409	21,878	414	49,207
Beneficiaries who lack capacity to manage their financial affairs	22	1,717	22	3,761
Total of Grants	431	23,595	436	52,968

*At point of allocation.

Restricted Funds: Government Grants

The four UK Health (and Social Care) Departments provide funding for the Health Grants to meet beneficiaries' health and wellbeing needs. In 2023 the governments of England, Scotland and Wales made a commitment to lifetime funding of the Health Grant, renewed the grant agreements for the first four-year period and agreed to review the level of funding at the end of the four-year period, based on beneficiary numbers and needs. During the year, the government of Northern Ireland aligned to the same lifetime commitment of funding and four-year grant agreement.

Health Grant funding is distributed in accordance with the Trust's existing distribution policy. The costs associated with administering the scheme are met from the funding. Details of Health Grant direct and indirect costs are set out in note 6. The level of costs charged has been determined by reference to factors such as the time spent on Health Grant related work (both administering and monitoring /reporting activities).

Trust staff and Beneficiary Representatives meet with each of the Health (and Social Care) Departments on an ongoing basis. One of the key objectives of these reviews and the related discussions is to actively manage the level of support requested from the four UK Health (and Social Care) Departments and the level and nature of the Health Grant fund expenditure such that there are no long-term deficits, or surpluses, on the restricted Health Grant funds.

Health Grants by Country

	England	Scotland	Wales	N. Ireland	Total
£000s					£000s
Fund balances as at 1 October 2023	298	144	6	38	486
Incoming Health Grants	9,814	1,698	1,188	574	13,274
Health Grants Allocation	(9,545)	(1,545)	(1,150)	(553)	(12,793)
Interest income	220	23	29	10	282
Health Grants - Direct costs	(58)	(89)	(7)	(3)	(157)
Health Grants – Indirect costs	(291)	(47)	(23)	(11)	(372)
Fund balances as at 30 September 2024	438	184	43	55	720

Notes to the financial statements for the year ended 30 September 2024 (continued)

6. Trust costs and net income

		2024			2023		
	Note	Unrestricted £000s	Restricted £000s	Total £000s	Unrestricted £000s	Restricted £000s	Total £000s
Expenditure on raising funds:							
Investment management fees		260	-	260	272	-	272
Support costs (see below)	4	52	-	52	44	-	44
Total Expenditure on raiding funds		312	-	312	316	-	316
Charitable activities:							
Grants	5,12	23,595	12,793	36,388	52,968	12,795	65,762
Net decrease in memorandum account balances	11,12	496	-	496	103	-	103
Subtotal		24,091	12,793	36,884	53,071	12,795	65,865
Costs of grant making (see below)		82	23	105	137	33	170
Beneficiary support costs (see below)		1,319	411	1,730	1,015	344	1,360
Support costs (see below)		326	95	421	291	82	373
Total Charitable activities		25,818	13,322	39,140	54,514	13,254	67,768

2024

	Staff and other HR costs	Admin and running costs	Legal, Professional and Audit fees	Beneficiary Engagement	Campaigning Costs	Research & Development	Total Unrestricted	Restricted costs allocation
	£000s	£000s	£000s	£000s	£000s	£000s	£000s	£000s
Expenditure on raising funds:								
Investment management	8	3	40	-	-	-	52	-
Expenditure on charitable activities:								
Costs of grant-making	57	18	7	-	-	-	82	23
Beneficiary support costs	697	613	4	-	-	5	1,319	411
Other costs:								
- Governance & admin	184	47	43	18	-	-	292	
- New claims	16	18	-	-	-	-	34	
- Campaigns	-	-	-	-	-	-	-	
Total other costs	200	65	43	18	-	-	326	95
Total unrestricted costs	962	699	95	18	-	5	1,779	
Restricted costs								
Beneficiary support costs	312	193	16	8	-	-	529	529
- Health Grant recharged								
Total costs – 2024	1,274	892	111	26	-	5	2,308	
Total costs - 2023 (see below)	1,243	510	151	17	7	18	1,947	

Notes to the financial statements for the year ended 30 September 2024 (continued)

6. Trust costs and net income (continued)

Comparative 2023	Staff and other HR costs	Admin and running costs	Legal, Professional and Audit fees	National Advisory Council	Campaign ing Costs	Research & Development	Total Unrestricted	Restricted costs allocation
	£000s	£000s	£000s	£000s	£000s	£000s	£000s	£000s
Expenditure on raising funds:								
Investment management	6	4	34	-	-	-	44	-
Expenditure on charitable activities:								
Costs of grant-making	81	19	38	-	-	-	137	33
Beneficiary support costs	684	304	5	3	-	18	1,015	344
Other costs:								
- Governance & admin	152	38	48	14	-	-	252	
- New claims	18	12	-	-	-	-	30	
- Campaigns	1	-	-	-	7	-	9	
Total other costs	171	51	48	14	7	-	291	82
Total unrestricted costs	942	377	125	17	7	18	1,488	
Restricted costs								
Beneficiary support costs	301	133	26	-	-	-	459	459
- Health Grant recharged								
Total costs – 2023	1,243	510	151	7	7	18	1,947	

Net income for the year is stated after charging/crediting:

	2024 £000s	2023 £000s
Depreciation	41	34
Audit Fees	34	32
Profit on disposal of fixed assets	-	(8)

Notes to the financial statements for the year ended 30 September 2024 (continued)

7. Trustee and employee information

The monthly average number of persons employed by the Trust during the year was 21 (2023: 19).

Staff costs (for the above persons)	2024 £000s	2023 £000s
Gross salaries and wages	930	854
Social security costs	108	94
Employer pension contributions	93	83
Other employee benefits	32	32
	1,163	1,063

The number of employees whose total emoluments (i.e. salary and taxable benefits) exceeded £60,000 were:

	2024 Number	2023 Number
£60,001 - £70,000	1	1
£80,001 - £90,000	2	2
£110,001 - £120,000	0	1
£120,001 - £130,000	1	0

No remuneration was paid to the Trustees of The Thalidomide Trust Company Ltd (2023: £nil). Travel and subsistence expenses of £7,000 (2023: £7,000) were reimbursed to 6 (2023: 5) Trustees of The Thalidomide Trust Company Ltd during the year.

The total remuneration and benefits received by the Trust's key management personnel was £330,000 (2023: £318,000) for 3 employees (2023: 3).

8. Tangible assets

Tangible assets comprise the following:

	Motor Vehicles	Furniture & equipment	Office Building	Office Refurb	Total
	£000s	£000s	£000s	£000s	£000s
Cost					
At 1 October 2023	26	12	465	159	662
Additions	-	-	-	-	-
Disposals	-	-	-	-	-
At 30 September 2024	26	12	465	159	662
Accumulated depreciation					
At 1 October 2023	8	6	194	11	219
Charged	7	2	9	23	41
Disposals	-	-	-	-	-
At 30 September 2024	15	8	203	34	260
Net book value					
At 30 September 2024	11	4	262	125	402
At 30 September 2023	18	6	271	148	443

All tangible fixed assets are unrestricted.

9. Investments

	2024 £000s	2023 £000s
Unlisted investments		
Equities	100,895	103,634
Fixed Income	52,649	42,090
Cash held for investments (including accrued investment income)	1,365	893
Total per Balance Sheet	154,909	146,616

All equities and fixed income are held in Global Unit Trusts.

All investments are held as unrestricted funds.

Notes to the financial statements for the year ended 30 September 2024 (continued)

9. Investments (continued)

The movement on investments in the year was as follows:

	2024 £000s	2023 £000s
Market value b/fwd 1 October 2023	146,616	170,591
Less: Disposal proceeds/ share exchanges	(25,303)	(74,466)
Add: Purchases at cost/share exchanges	14,180	37,591
Realised and unrealised gains/(losses)	18,944	13,273
Increase/(decrease) in cash held for investment (including accrued investment income)	472	(373)
Market value at 30 September 2024	154,909	146,616
Historical cost at 30 September 2024	121,523	127,061

The Trustees believe that the carrying value of the listed investments is supported by the underlying net assets.

10. Subsidiary

The valiDATE Trust was established on 7 August 2019 as a Private Limited Company by guarantee. The Thalidomide Trust has taken advantage of the exemption under section 24.13A of the Charities SORP, and not consolidated the results of valiDATE Trust in the Group financial statements.

ValiDATE Trust was established by the Trustees of the Thalidomide Trust with the intention of making its diagnostic algorithm available to other countries receiving applications from potential thalidomide survivors as an initial screening tool. During the year, the Directors of valiDATE Trust and the Trustees of the Thalidomide Trust agreed that maintaining valiDATE as a separate legal entity (with associated costs) was not financially viable, and the algorithm (intangible asset) and its activity were transferred to the Thalidomide Trust on 18 June 2024. The net book value of valiDATE Trust's intangible asset, which amounted to £1,000 at 30 September 2024, has been expensed in full in the accounts due to the unlikelihood of any significant future economic benefit flowing from it.

ValiDATE Trust ceased trading on 30 June 2024. The Directors of valiDATE Trust and the Trustees of the Thalidomide Trust have agreed to strike off valiDATE Trust.

At the 30 September 2024, valiDATE Trust owed the parent company, The Thalidomide Trust, £33,000 (2023: £38,000).

Notes to the financial statements for the year ended 30 September 2024 (continued)

10. Subsidiary (continued)

The results of validATE Trust for the period ended 30 September 2024 are shown below.

	2024
	£
Turnover and other income	13,185
Cost of sales and expenses	(10,852)
Profit for the year	2,333
Profit and loss reserves	(12,109)

11. Trust Fund including comparatives

	Unrestricted Funds			
	Designated Beneficiary Memorandum Accounts £000s	General Fund £000s	Restricted Fund £000s	Total Trust Funds £000s
Balance as at 1 October 2023	3,499	128,815	486	132,800
Net incoming/(outgoing) resources as per Statement of Financial Activities	-	9,422	234	9,656
Adjustment for net increase in beneficiary memorandum accounts (note 12)	(496)	496	-	-
Balance as at 30 September 2024	3,003	138,733	720	142,456
	Note 12		Note 5	

Notes to the financial statements for the year ended 30 September 2024 (continued)

11. Trust Fund including comparatives (continued)

	Unrestricted funds			
	Designated Beneficiary Memorandum Accounts £000s	General Fund £000s	Restricted Fund £000s	Total Trust Funds £000s
Fixed Assets				
Tangible	-	402	-	402
Investments	2,261	152,649	-	154,909
Current Assets				
Debtors and Prepayments	-	125	-	125
Advance of Grants	-	1,032	-	1,032
Cash at Bank and in Hand	742	3,088	7,550	11,380
Creditors: amounts falling due within one year				
Beneficiary nominee accounts	-	(18,319)	(6,830)	(25,149)
Creditors and accrued expenses	-	(243)	-	(243)
Balance as at 30 September 2024	3,003	138,733	720	142,456
	Note 12		Note 5	

	Unrestricted funds			
	Beneficiary Memorandum Accounts £000s	General Fund £000s	Restricted Fund £000s	Total Trust Funds £000s
Comparatives				
Balance as at 1 October 2022	3,602	153,642	566	157,810
Net incoming/(outgoing) resources as per Statement of Financial Activities	-	(24,930)	(80)	(25,010)
Adjustment for net increase in beneficiary memorandum accounts	(103)	103	-	-
Balance as at 30 September 2023	3,499	128,815	486	132,800
	Note 12		Note 5	

Notes to the financial statements for the year ended 30 September 2024 (continued)

11. Trust Fund including comparatives (continued)

Comparatives	Unrestricted funds		Restricted Fund £000s	Total Trust Funds £000s
	Beneficiary memorandum Accounts £000s	General Fund £000s		
Fixed Assets				
Tangible	-	443	-	443
Investments	2,382	144,234	-	146,616
Current Assets				
Debtors and Prepayments	-	108	7	115
Advance of Grants	-	765	-	765
Cash at Bank and in Hand	1,117	5,540	7,624	14,281
Creditors: amounts falling due within one year				
Beneficiary nominee accounts	-	(22,038)	(7,145)	(29,183)
Creditors and accrued expenses	-	(237)	-	(237)
Balance as at 30 September 2023	3,499	128,815	486	132,800
	Note 12		Note 5	

12. Beneficiary accounts

	Beneficiary memorandum accounts £000s	Beneficiary nominee accounts £000s	Beneficiary Health Grant accounts £000s	Total 2024 £000s	Total 2023 £000s
As at 1 October 2023					
Balance Sheet- Beneficiary Nominee Accounts		22,038	7,145	29,183	22,646
Balance Sheet- Beneficiary Memorandum Accounts	3,499				
Annual Grant Allocations	369	23,226		23,595	21,865
Lump Sum 2023 Allocations	-	-		-	31,103
Health Grant Allocations			12,793	12,793	12,795
Payments from Beneficiary Accounts	(706)	(27,104)	(13,108)	(40,918)	(59,329)
Transfers between Nominee and Memorandum Accounts	(159)	159			
Adjustment for net decrease/ (increase) in Beneficiary Memorandum Accounts				-	103
As at 30 September 2024:					
Balance Sheet- Beneficiary Nominee Accounts		18,319	6,830	25,149	29,183
Balance Sheet- Beneficiary Memorandum Accounts	3,003				
	Note 11				

Notes to the financial statements for the year ended 30 September 2024 (continued)

12. Beneficiary accounts (continued)

Beneficiary Memorandum Accounts are all designated funds and include: accounts for beneficiaries who lack capacity to manage their financial affairs (as detailed at note 5) and lump sum compensation payments allocated to new beneficiaries accepted by the Trust. On the death of a beneficiary, any funds held in Memorandum Accounts revert to the General fund to be used for the benefit of the wider community.

Beneficiary nominee accounts include the Annual Grant funds to which a beneficiary has absolute entitlement and which have not been requested by beneficiaries at the year-end (as detailed in note 5). On the death of a beneficiary, any Annual Grant funds not yet paid out will form part of their estate.

Beneficiary Health Grant accounts include the Health Grant funding made available, but not requested by beneficiaries (as detailed in note 5). On the death of a beneficiary, any Health Grant funds not yet paid out are repaid to the respective government.

13. Taxation

The Trust is a registered charity, and as such is entitled to certain tax exemptions on income and profits from investments, and surpluses on any trading activities carried on in furtherance of the charity's primary objectives, if these profits and surpluses are applied solely for charitable purposes.

During the current and prior years, all distributions to beneficiaries were paid under the terms of Statutory Instrument 2004 No 1819, which allows distributions from the Trust to be paid free of income tax, and therefore no income tax liability arose.

14. Pension obligations

Defined contribution scheme

Permanent staff are eligible to receive a pension provision equivalent to 10% of gross salary under a defined contribution scheme. During the year employer contributions to this scheme amounted to £93,000 (2023: £83,000). At the end of the year other creditors and accruals included £13,000 (2023: £12,000) payable in respect of employer pension contributions.

15. Debtors

	Total funds 2024 £000s	Total funds 2023 £000s
Advances of Grants		
amounts falling due within one year	267	214
amounts falling due after one year	765	551
Other debtors	35	44
Prepayments and accrued income	90	64
Total	1,157	873

Notes to the financial statements for the year ended 30 September 2024 (continued)

15. Debtors (continued)

As set out in note 5, the Trustees will consider requests for Major Advances, Short-Term and Emergency Advances. The current Advances consist of Major Advances and Emergency Advances balances as at 30 September 2024. Advances are recoverable from future Annual Grant allocations. Emergency Advances are recoverable within one year, Major Advances are recoverable up to a maximum of ten years.

16. Creditors

	Total funds 2024 £000s	Total funds 2023 £000s
Creditors: amounts falling due within one year		
Beneficiary nominee accounts (note 12)	25,149	29,183
Other creditors and accruals	243	230
Total	25,392	29,413

17. Net Debt Disclosure

	At 1 October 2023	Cash-flows	Other non- cash changes	At 30 September 2024
	£	£	£	£
Cash	14,281	(2,901)	-	11,380
Cash held for investment	893	472	-	1,365
Total	15,174	(2,429)	-	12,745

18. Related Party Transactions

Other than expenses paid to Trustees (see note 7), there were no related party transactions during the year.

During the period, the charity made payments for expenditure of its subsidiary, valiDATE Trust of £0 (2023: £0).

At the year end, the Trust was owed £33,000 (2023: £38,000) from the valiDATE Trust. This balance is presented within other debtors.

There is no parent undertaking. The ultimate controlling party is The Thalidomide Trust Company Ltd.

Notes to the financial statements for the year ended 30 September 2024 (continued)

19. Comparatives for Statement of Financial Activities

Comparatives	Note	Unrestricted Funds £000s	Restricted Funds £000s	Total Funds 2023 £000s
Income from:				
Diageo donations	3	11,666	-	11,666
Health Department Grants	5	-	13,037	13,037
Investment income	2	4,886	137	5,023
Other income		75	-	75
Total		<u>16,627</u>	<u>13,174</u>	<u>29,801</u>
Expenditure on:				
Raising funds (solely investment management fees)	6	(316)	-	(316)
Charitable activities	6	(54,514)	(13,254)	(67,768)
Total		<u>(54,830)</u>	<u>(13,254)</u>	<u>(68,084)</u>
Net gains/(losses) on investments	9	13,273	-	13,273
Net income (expenditure)		<u>(24,930)</u>	<u>(80)</u>	<u>(25,010)</u>
Reconciliation of Funds				
Fund balances brought forward At 1 October 2022	11	157,244	566	157,810
Fund balances carried forward at 30 September 2023	11	<u>132,314</u>	<u>486</u>	<u>132,800</u>

THE THALIDOMIDE TRUST

England & Wales - Charity number 266220

Accounts

The Thalidomide Trust

Annual Report and Financial Statements
for the year ended 30 September 2023

Registered Charity Number 266220

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Reference and administrative details

Registered Name	The Thalidomide Trust
Charity number	266220
Registered address	1 Eaton Court Road Eaton Socon St Neots Cambridgeshire PE19 8ER
Corporate Trustee	The Thalidomide Trust Company (incorporated on 19 January 2018 with Company Number 11160424, registered address as above)

Directors of the Corporate

Company

The Directors of The Thalidomide Trust Company during the year and up to the date of approval were:

Mark Spofforth OBE BSc FCA CTA FRSA (Chair of Trustees)
Sir Robert Nelson QC – resigned 31 March 2023
Kevin Wesbroom MA MA FIA – resigned 31 December 2022
Mark Benstead MA MBA
David Body MA Solicitor of Senior Courts of England & Wales
Professor Adrian Charles Newland CBE
Professor William Andrew Owens MD FRCS(CTh)
Professor Rosemary Varley
Ruthe Isden
Shan Abdullah
Dame Caroline Swift – appointed 1 January 2023

Senior Management Team	Deborah Jack - Executive Director Katy Sagoe - Director of Health & Wellbeing Suzanne Lluch - Finance Director
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Medical Advisers	Dr Dee Morrison MB ChB (to 31 May 2023) Dr Susan Brennan MBChB MRCP Dr Helen Smith MBChB MRCP Dr Tim Fenn MB BS (from 13 June 2023)
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Chair of NAC	Rowland Bareham (to 19 April 2023) Geoff Spink (from 19 April to 31 August 2023)
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Investment Managers

BlackRock
12 Throgmorton Avenue
London
EC2N 2DL

TwentyFour Asset Management
8th Floor
The Monument Building
11 Monument Street
London EC2R 8AF

Schroders Investment Management Limited
1 London Wall Place
London Wall
London
EC2Y 5AU

Legal & General Investment Management
One Coleman Street
London
EC2R 5AA

Investment Consultants

Hymans Robertson
45 Church Street
Birmingham
B3 2RT

Solicitors

Withers
20 Old Bailey
London
EC4M 7AN

Hewitsons
Shakespeare House
42 Newmarket Road
Cambridge
CB5 8EP

Actuaries

Hymans Robertson
20 Waterloo Street
Glasgow
G2 6DB

Bankers

Lloyds Bank
39 Threadneedle Street
London
EC2R 8AU

Independent auditors

Saffery LLP
Westpoint
Peterborough Business Park
Lynchwood
Peterborough PE2 6FZ

Annual Report

Objectives and activities

The Thalidomide Trust (“the Trust”) was established to provide ‘relief and assistance’ to individuals with disabilities caused by their mothers taking, during pregnancy, a preparation distributed by The Distillers Company (Biochemicals) Limited in the United Kingdom containing the drug known as thalidomide in the late 1950s and early 1960s.

Our aims

Almost all our beneficiaries are now in their early 60s and most are feeling the impact of using their bodies in ways for which they were never designed. In addition, as they get older, they are experiencing a wide range of age-related health problems that are exacerbated by their original thalidomide damage. This seriously impacts on their quality of life and their ability to remain fully independent. A small number have experienced a cognitive decline alongside their deteriorating physical health and this has resulted in very complex care needs.

The Trust meets the increasingly complex needs of the beneficiary community through the provision of financial support – in the form of annual grant payments – and a range of information, advice and advocacy services. To underpin this, we gather evidence on the needs and experience of our beneficiaries and undertake more detailed research on topics that are of greatest relevance to them.

The Trust has a Vision and five Strategic Goals which were jointly developed – and reviewed and updated in 2022 – by the Trustees, staff and National Advisory Council (NAC) of beneficiary representatives:

Our Vision is that each and every beneficiary of the Trust has access to the resources and support they need to live their best life for the longest time.

Our five strategic goals are.....

- | | |
|----------------|--|
| GOAL 1: | To ensure the Trust’s income is secure, financial risk is effectively managed and adequate funding is available to meet the increasing needs of beneficiaries as they age. |
| GOAL 2: | To apply the Trust’s resources strategically, effectively and equitably (in order to achieve our vision). |
| GOAL 3: | To ensure that all beneficiaries have access to the best possible information, advice, advocacy, services and support – both within and outside the Trust – as they age and their physical and mental health needs increase. |
| GOAL 4: | To ensure effective (two-way) sharing of knowledge and learning for the benefit of the beneficiary community and for wider public benefit. |
| GOAL 5: | To ensure that the individual beneficiary’s needs remain paramount, even when third parties (families, carers, representatives) have a role in acting on their behalf. |

Public Benefit

Although the Trust is very much focussed on the needs of a small, discrete community of beneficiaries, we also take steps to deliver a broader public benefit by sharing our research and learning with other thalidomide organisations around the world and, where relevant, with the broader disability community.

The Trust is increasingly aware of the benefit of sharing our experience and lessons learned from fifty years of supporting this unique community with other groups of individuals living with disabilities and the organisations that support them. During the year, staff and Trustees shared information on how we support our beneficiaries with the Patient Safety Commissioner to inform their thinking around options for redress for those affected by sodium valproate and pelvic mesh. We have also commenced a new 'Legacy Project' to document the key lessons we have learned that we feel will be most valuable to others in the future.

Structure, Governance and Management

Structure

The Thalidomide Trust was set up in 1973 - originally as the Thalidomide Children's Trust - and is a charitable discretionary Trust registered with the Charity Commission for England and Wales.

With the consent of the Charity Commission, on 29 January 2018 a new company limited by guarantee, The Thalidomide Trust Company (incorporated on 19 January 2018, Company Number 11160424), was appointed as sole Corporate Trustee of the Trust, replacing the individual Trustees. The Corporate Trustee will be referred to in this document as the Trustee.

The Trustees at the date of incorporation became the Directors of the Company. However, although legally Directors, in recognition of the fact that they function as Trustees and operate within the legal frameworks and guidance of the Charity Commission, they continue to be referred to as Trustees. To reflect this, they are referred to as Trustees (as opposed to the Trustee above) throughout this Annual Report.

During 2019/20, we set up a new company limited by guarantee as a subsidiary of the Thalidomide Trust, with the consent of the Charity Commission. The validATE Trust (registered in England and Wales, with company number 12144047) operates on a not-for-profit basis. It was established specifically to oversee the maintenance and development of an online tool to be used by qualified clinicians to screen individuals using detailed medical data in order to assess the likelihood of Thalidomide Embryopathy (TE). This Diagnostic Algorithm for Thalidomide Embryopathy was one of the key outputs of a meeting of international thalidomide experts organised by the World Health Organisation (WHO) and is designed to be used worldwide to ensure consistent diagnosis of TE, based on the latest international evidence.

Trustees (formally Directors of the Trustee Company)

The Trust is governed by a small, highly-skilled Board who bring a wealth of experience and expertise to the charity including medical, legal, research, governance, health and social care policy, financial management, actuarial and investment.

Trustees are appointed through a structured recruitment process which focusses on the skills required to meet the current and future needs of beneficiaries. The recruitment process is overseen by the Trust's Chair and there is direct beneficiary involvement in all Trustee appointments.

The Trust has a well-defined and comprehensive programme of induction for new Trustees and all new Trustees are offered a mentor from within the existing Trustee Board.

The Trustees are legally responsible for the overall management and control of the Trust and meet as a full Board at least three times a year. One of these three meetings is an Awayday which enables the Trustees and the Trust's Senior Management Team to spend dedicated time focussing on long term strategic issues.

The Trust has two key Standing Committees - the Health & Wellbeing Committee and the Finance Committee - which met two and four times respectively during this year. Both Committees are attended by beneficiary representatives. The Health & Wellbeing Committee is jointly-chaired by a Trustee and a beneficiary.

There are two additional Committees which met on an ad hoc basis during 2022/23. They are:

- Claims Committee, which considers all evidence and makes recommendations to the Board regarding whether applicants should be accepted as new beneficiaries of the Trust.
- Research Committee, which oversees all research involving the Trust and its beneficiaries and commissions and shapes new research projects.

Independent Governance Review

In late 2022, the Trust commissioned a comprehensive Independent Governance Review. Following a competitive tendering exercise, Compass Partnership were appointed to undertake the review which involved both quantitative and qualitative data gathering and involved Trustees, senior staff and existing and former members of the National Advisory Council (NAC).

The findings of the review were largely positive, with the Trust performing favourably against the benchmark of other – primarily larger – charities for whom Compass had carried out similar reviews.

Compass identified a number of opportunities to further strengthen the charity's governance arrangements – some of which have already been introduced - but the key recommendation for change related to the way the Trustees engage with the Trust's beneficiaries, and this has been a significant new area of work in 2023.

Beneficiary Engagement

For more than 40 years, the Trust has had a National Advisory Council (NAC) – a small group of elected beneficiaries whose role was to advise Trustees on a wide range of issues from a beneficiary perspective to inform their decision-making.

The Independent Governance Review identified a number of significant limitations of the NAC as a mechanism for ensuring that Trustees understand the needs and lived experiences of the whole beneficiary community, especially as beneficiaries age and their needs become both greater and more diverse.

The Review recommended that Trustees introduce new ways of hearing directly from a greater number, and a broader range, of beneficiaries so that when they make important decisions, they do so in the confidence that they have a good understanding of the lived experience and changing needs of beneficiaries.

Before making any changes, Trustees had a series of meetings with NAC members, asked the staff for ideas and undertook a consultation with all beneficiaries to seek their views on future beneficiary engagement. 68% of beneficiaries responded to the consultation and the findings shaped a new approach to beneficiary engagement which was agreed by the Trustees at an Away Day which focused specifically on this topic.

The new approach to beneficiary engagement is intended to complement and enhance the data on beneficiary needs gathered in other ways. It is designed to enable Trustees to hear directly from a wide range of beneficiaries and to offer beneficiaries a number of different ways of getting involved and having their voices heard.

The new beneficiary engagement mechanisms, which replace the NAC, are:

- A **Beneficiary Insights Panel**, comprised of up to 25 beneficiaries who are broadly representative of the community in terms of type of thalidomide damage, gender, geographic location and length of time as a beneficiary. The role of Panel Members is to share their personal views and lived experience with Trustees and to highlight emerging issues and concerns.
- Periodic **Trustee Webinars** to provide an opportunity for two-way communication between Trustees and beneficiaries.
- **Beneficiary Focus Groups** on different topics or with different groups within the beneficiary community to enable Trustees to better understand their specific needs.
- **Task & Finish Groups** made up of beneficiaries and staff to undertake specific projects.
- **Beneficiary Representatives on Committees** to ensure that there is always a beneficiary perspective included in important discussions.
- **Periodic Beneficiary Surveys and Consultations**

The first Trustee Webinar took place in September 2023 and feedback from beneficiary attendees was overwhelmingly positive – with 100% of the beneficiaries who provided feedback saying that they were likely to attend a future Trustee Webinar.

It is expected that the first Beneficiary Insights Panel will take place in February 2024.

The Trustees are committed to reviewing the new arrangements in late 2025 to see if they have resulted in more effective beneficiary engagement and will make changes to the current initiatives or try out new ideas, if necessary.

Staff Team

The day to day running of the Trust is delegated to the Executive Director, supported by a small, dedicated and skilled staff team.

The majority of staff are focussed on supporting beneficiaries in relation to their health and wellbeing in order to maximise their independence and quality of life.

In 2023, the Trust participated for the first time in the 'Best Employer' (Eastern Region) initiative. We scored particularly highly on our clarity of vision, culture & values, beneficiary focus, motivation, team-work and organisational engagement and were delighted to be awarded Platinum accreditation award – the highest level awarded.

Remuneration Policy

The Trustees are responsible for the Trust's remuneration policy as well as agreeing annual pay increases for the staff team. Trustees take account of market conditions and the pay practice of other comparable charities and employers in the geographic area.

Volunteers

A number of beneficiaries generously volunteer their time and expertise to support the Trust and, through it, the broader beneficiary community.

In the last 12 months over 30 beneficiaries volunteered their time in a wide range of roles including: providing (practical and emotional) peer support; hosting virtual discussions/events for beneficiaries; membership of the NAC; and attending meetings with the four UK Health (and Social Care) Departments.

Beneficiaries

The Trust has responsibility for assessing new applications to become beneficiaries of the Trust and has established a robust procedure for assessing new applications, drawing on international evidence and utilising the diagnostic algorithm, valiDATE, which was one of the key outputs of the WHO conference on Thalidomide Embryopathy held in early 2014.

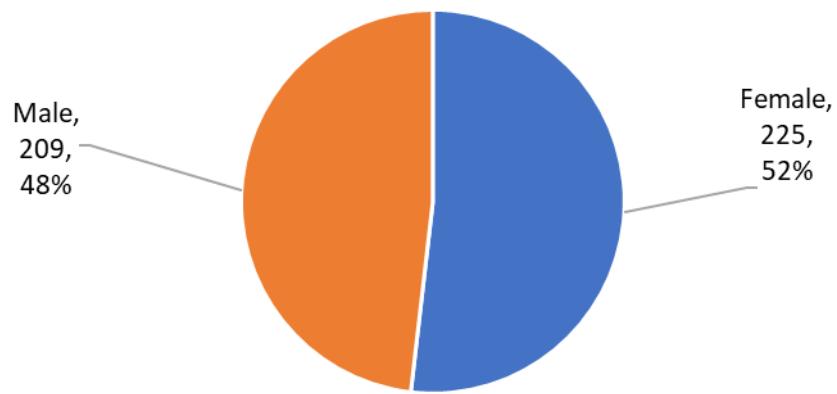
During the year, the Trust received 30 completed applications from individuals who thought they may be entitled to become beneficiaries, however, no applicants met the necessary criteria for acceptance in the twelve-month reporting period.

It is with regret that the Trustees report the deaths of four beneficiaries during the year.

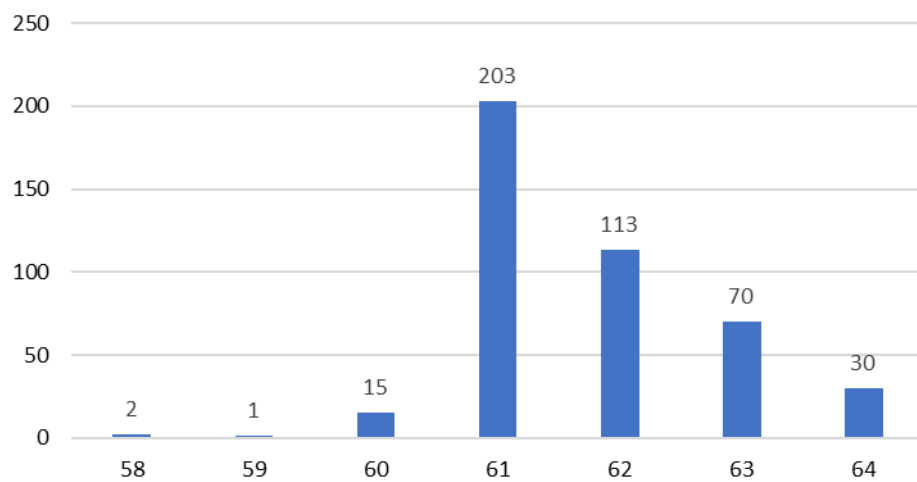
At 30 September 2023 there were 434 beneficiaries (2022: 438).

The charts on the following page provide a breakdown of beneficiaries by gender, age and country of residence as at 30 September 2023.

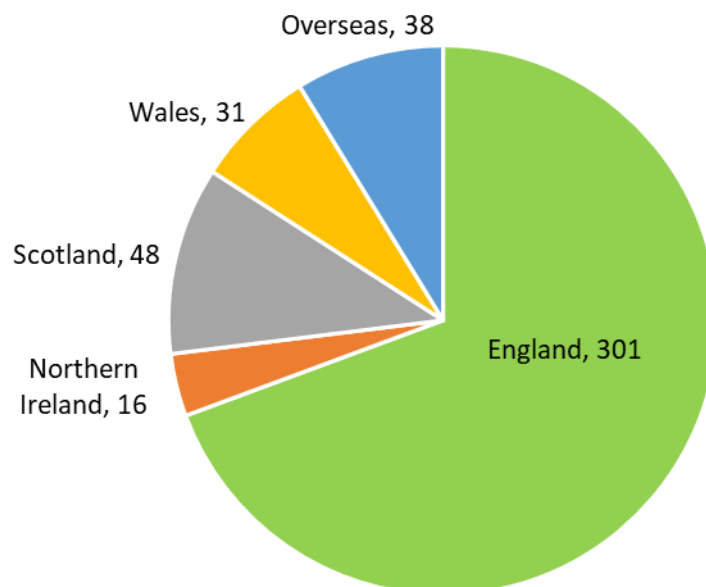
Gender of Beneficiaries



Age of Beneficiaries



Country of Residence



Risk Management

A key role of Trustees is to identify and manage risk and they discharge this duty by means of a Risk Register. The full Risk Register is reviewed by Trustees annually. The most significant risks are reviewed by the Finance Committee on a quarterly basis. This year, the Trustees have satisfied themselves that adequate systems and procedures are in place to manage all of the identified risks.

As a result of their sustained and proactive approach to risk management, there is only one risk identified as high and that relates to managing the significant change in the way Trustees engage with beneficiaries – both ensuring that the new beneficiary engagement initiatives provided greater inclusivity and genuine participation, and managing the relationship with those beneficiaries who were members of the National Advisory Council (NAC) to avoid them feeling alienated.

In terms of ongoing risk management, we continue to review and strengthen our IT security arrangements by providing regular cyber security awareness training for staff and Trustees and undertaking external penetration testing and phishing simulation campaigns. Following a comprehensive external GDPR Review last year, we have updated and further strengthened our data protection policies and processes and are confident that we are GDPR-compliant.

The Trustees treat safeguarding of our beneficiaries as an important priority and have a robust safeguarding policy in place. Sadly, during the 12-month reporting period, in four cases safeguarding concerns involving family members or carers were identified and reported to external bodies (Local Authority Safeguarding leads and/or the Police).

Achievements and Performance

We continue to gather robust data on our beneficiaries' evolving needs through our structured programme of face-to-face Holistic Needs Assessments and this evidence informs the development of our own services and support and also our discussions with funders.

Last year we successfully concluded our four-yearly Diageo Chairs Review where we had the opportunity to share the latest evidence of beneficiaries changing needs. This was instrumental in us securing additional resources which enabled us to make both a one-off lump sum payment to all beneficiaries and increase the level of health and wellbeing support that we are able to provide to beneficiaries for the next four years.

We also signed agreements with the Health (& Social Care) Departments in England, Scotland and Wales which reflect their life time commitment to Health Grant funding for beneficiaries and the level of funding for the current four-year period.

We continue to provide a wide range of ongoing support to our beneficiaries, tailored to meet their individual needs and, now that they are almost all in their 60s and experiencing the usual health issues associated with ageing, their needs are becoming increasingly complex and multi-layered.

Over the 12-month period, 287 individual beneficiaries (over 65% of the beneficiary community) had contact with our Health & Wellbeing Team, many on multiple occasions. The most common issues that beneficiaries require support with are health issues – including access to NHS services - care and carers, benefits and mental health/emotional support – these issues account for over 80% of contacts with the Health & Wellbeing Team.

In addition to providing significant day-to-day support, at the start of the year we identified a number of ambitious goals for 2022/23. These are set out below together with an overview of the progress made over the last 12 months:

We said we would...	We ...
.... commission research into pain management with a view to developing a new bespoke model of pain management for beneficiaries.	 undertook a competitive tendering exercise and appointed the University of Nottingham to undertake a detailed pain management research project.
.... refine the data we gather from beneficiaries at Holistic Needs Assessments (HNAs) to deepen our understanding of their future needs.	... undertook a comprehensive review of the data we collect and introduced a number of new areas where we are keen to gain a more in-depth understanding including future housing needs and beneficiaries' wellbeing and social connections.
... complete and launch a new resource for frontline care staff to increase their understanding of thalidomide damage and the impact it has on daily life.	... are close to finalising the new resource, having sought feedback from a number of beneficiaries and their carers.
.... undertake an independent review of our governance arrangements.	... commissioned an Independent Governance Review in late 2022 and have already implemented a significant number of the recommendations, including strengthening our beneficiary engagement activities.
..... secure a commitment to lifetime Health Grant funding from the Northern Ireland government.	.. unfortunately, have been unable to secure a life-time funding commitment due to the absence of a National Executive in Northern Ireland, empowered to make this decision. However, our dialogue is continuing.
..... develop a network of mental health specialists who understand the issues experienced by beneficiaries, including trauma.	.. created our Specialist Mental Health Network and launched this in Summer 2023.

Over the last 12 months, we also introduced a new Private Treatment Scheme – which enables beneficiaries to access essential treatment which is not available on the NHS in a reasonable timeframe - and undertook a survey of the health & wellbeing needs of our overseas beneficiaries to increase our understanding of these.

Plans for the Future

In the next 12 months, the Trustees and staff will continue to work together to implement our new, jointly owned Strategic Plan. Our plans include:

- Setting up a working group on Vehicles and Vehicle Adaptations and identifying 'beneficiary experts' to ensure that beneficiaries have the information and support they need to make decisions regarding appropriate vehicles and adaptations.
- Undertaking a review of post-66 benefit changes that will affect beneficiaries.
- Implementing the outstanding actions from our Independent Governance Review.
- Developing and embedding our new Beneficiary Insights panel.
- Delivering a preliminary evaluation of the Private Treatment Scheme and Specialist Mental Health Network (covering process, take-up and beneficiary experience).
- Developing tailored information for beneficiaries to enable them to understand and access the full range of NHS services that are available post-60 (e.g. health screening, immunisations, specialist clinics).

Financial Review

During the year the Trust allocated grants totalling £65.8m (2022: £32.1m) to its beneficiaries. This included an additional one-off lump sum grant payment in recognition of beneficiaries' increasing health and wellbeing needs. The Trust received donations from Diageo plc totalling £11.7m (2022: £15.1m). The decrease on the previous year was expected as following the actuarial review in 2016, Diageo uplifted its annual contributions by £3m (plus inflation) for an agreed 6-year period, which ended in 2022.

Health Grant funding from the four Health and Social Care Departments of the United Kingdom totalled £13.0m (2022: £12.6m). As Health Grant funding is provided for specific, agreed health and wellbeing purposes, these are accounted for by the Trust as funds restricted for these purposes.

The Trust is committed to managing its resources effectively and achieving value for money. It operates a robust budget management system which involves regular review of activity and expenditure by budget holders, oversight by the Management Team and regular reporting of variances to the Trust's Finance Committee. The Trust does not actively fundraise and 100% of its resources are utilised for charitable purposes, including charity governance. During 2022/23, 97% of outgoing resources were in the form of grants to our beneficiaries. Of the remaining 3% of expenditure, 70% (excluding investment management fees) was spent on providing health and wellbeing support and financial guidance directly to our beneficiaries by our staff and volunteers. The balance of resources was utilised to administer beneficiary grants, assess new claims, ensure effective governance of the Trust, and support agreed campaigning activities.

Investment Objectives

The principal objective of the investment policy is to generate sufficient income and capital return to enable the Trustees to pay Annual Grants for the entire lives of the beneficiaries.

The environmental, social and governance (ESG) nature of Trust investments has been considered at length by the Trustees. The Trustees believe that ESG-related risks, including climate change risks, are financially material and an important component of investment risk. The Trustees believe that organisations that soundly manage ESG-related risks are more likely to be financially sustainable over time, and therefore deliver better long-term risk-adjusted returns. Trustees currently hold £33.8m of funds in an ESG fund with Legal & General Investment Management (LGIM).

As all of the Trust investments are held within pooled funds, the decisions regarding the selection of investments is entrusted to the investment managers, who each act within agreed guidelines. Trustees regularly ask investment managers to explain how ESG factors are incorporated into their decisions regarding the selection of investments.

In line with the 2018 Covenant with Diageo, the Trustees have adopted an investment policy which will reduce the investment risk of the portfolio over the lifetime of the Trust. In order to achieve this, from 2017 to 2022 the Trustees continued to try to achieve higher returns with a given amount of risk, managed through diversification and active management of the investment assets. In 2023, in line with the strategy, trustees began the process of de-risking the portfolio with the long-term intention of achieving a low risk portfolio by 2037. The low risk portfolio is defined as a mixture of bonds, cash, swaps and other financial instruments with up to 10% in return-seeking assets, designed to provide

the anticipated future payments from the Trust with a significant degree of certainty. The de-risking carried out this year involved moving £15m from equities (held by Schroders, BlackRock and Legal & General Investment Management) into a new BlackRock fixed income fund structure. A further £22m was moved from existing credit funds (held by BlackRock and Twentyfour Asset Management) into the same BlackRock funds.

The current benchmark against which performance will be measured is represented by a portfolio comprising of 70% global equities and 30% bonds.

Investment Strategy and Performance

The investment strategy is currently implemented through a combination of investments and managers as set out in the table below, together with the ranges within which the policy is managed, in line with the Statement of Investment Principles dated September 2023.

Portfolio	Manager	Central Allocation (% of Assets)	Target Ranges (% of Assets)
Active Global Equities	Schroders	24.8	15-35
Passive Global Equities	BlackRock and LGIM	45.9	35-55
Bond Portfolios	BlackRock and 24AM	28.7	20-40
Cash	Lloyds, RLAM and within portfolios above	0.6	0-20

Cash deposits are held with a variety of banks and investment managers.

The total annual return on the Trust's investments for the year was 12.2% (2022: -5.8%) which is higher than the benchmark of 9.1%. Last year's negative return was due to the impact on the global markets of soaring inflation and higher borrowing costs. This affected markets most significantly around the end of September 2022, but markets gradually recovered over the following few months.

Over the last three years the average rate of return has been 11.0% pa, which is higher than the benchmark of 8.4%.

Significant Investments

At the year end, the following investments represented 5% or more of the total market value of investments:

	£000s	%
Legal and General Future World ESG Fund	33,829	23
Schroders Global Recovery Fund	27,261	19
BlackRock North America Fund	21,785	15
BlackRock Global Corporate ESG Bond	17,994	12
BlackRock Overseas Government Bond	17,334	12
Schroders Charity Equity Fund	9,158	6

Derivative Instruments

The Trustees have authorised Schroders to use financial contracts, known as derivatives, to help manage investment portfolio risk. At the year end the open derivatives position was a net liability of £0 (note 9) (2022: £0).

Diageo Covenant

A Deed of Covenant is in place, signed by the Trustees and Diageo plc (successor to The Distillers Company), which sets out Diageo's commitment to long-term support for Thalidomide Trust beneficiaries and to underwrite the investment policy of the Trust. The Covenant enables the Thalidomide Trust both to maintain the programme of Annual Grants to its beneficiaries and deliver ongoing support in response to their evolving and growing health and wellbeing needs.

The Deed of Covenant is reviewed by the Trustees, beneficiary representatives and Diageo periodically. In January 2018, an updated Deed of Covenant was agreed which reflects an increased level of support from Diageo.

In February 2023, an additional lump sum grant payment was made to beneficiaries in recognition of their increasing health and wellbeing needs as they get older. These funds were taken from the Trust's existing investment portfolio, as agreed with Diageo. In addition, Diageo agreed additional funding to meet specific health and wellbeing needs that the Trust was able to evidence from the Holistic Needs Assessments carried out over the preceding six years.

Government Health Grants

In addition to the assets held by the Trust and the income from Diageo, the UK government supports the Trust by way of Health Grant funding agreements in place with the four UK Health and Social Care Departments since 2009. This money has helped beneficiaries to respond to their growing needs as they age – in order to maximise their independence and quality of life, minimise further deterioration and improve their overall health and wellbeing. In March 2021, the Chancellor, Rishi Sunak, announced a commitment to lifetime funding of the Health Grant to beneficiaries living in England and during 2022 both Wales and Scotland announced the same commitment. In 2023, new 4-year Health Grant agreements were signed by the Health (and Social Care) Departments in England, Scotland and Wales which cover the period to 2027. Discussions are still underway with the Northern Ireland government over a similar lifetime commitment and grant agreement for beneficiaries living in Northern Ireland but the absence of a National Executive has impeded progress. However, the Northern Ireland government made a grant payment, in line with those made by the other three nations, to beneficiaries in Northern Ireland in 2023.

Grant Making and Reserves Policy

Beneficiaries receive an Annual Grant, based on their level of disability, from funds that come from Diageo each year in line with the Covenant and the Trust's reserves, including the interest and investment growth accrued.

The Trustees' distribution policy continues to provide individual Annual Grants to beneficiaries for the whole of their lives. The Trustees have to set a policy which will ensure reserves are not depleted whilst beneficiaries are in need of funding, whilst at the same time aiming to ensure that all assets are utilised by the time of the death of the last

beneficiary. The total unrestricted funds at 30 September 2023 stood at £132m (2022: £157m) whereas the Restricted Fund had a balance of £0.5m at the year-end (2022: £0.5m).

Statement of the Corporate Trustee's Responsibilities

The Trustee is responsible for preparing the Trustee's Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England and Wales requires the Trustee to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and their application for that period.

In preparing these financial statements, the Trustee is required to:

- select suitable accounting policies and then apply them consistently
- observe the methods and principles in the Charities SORP (Statement of Recommended Practice)
- make judgments and estimates that are reasonable and prudent
- state whether applicable accounting standards, comprising FRS 102, have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis¹ unless it is inappropriate to presume that the charity will continue in business.

The Trustee is responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable it to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. The Trustee is also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustee is responsible for the maintenance and integrity of the charity and financial information included on the charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Signed on behalf of the Corporate Trustee:

Mark Spofforth

Chair of the Board of the Thalidomide Trust Company

30 January 2024

¹ The going concern basis means that the charity has the resources to continue in operations for a minimum of 12 months from the date of signing these financial statements

Independent auditors' report to the trustee of The Thalidomide Trust

Report on the audit of the financial statements

Opinion

We have audited the financial statements of The Thalidomide Trust for the year ended 30 September 2023 which comprise the balance sheet as at 30 September 2023; the statement of financial activities for the year then ended; cashflow statement for the year and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102, the Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 30 September 2023 and of its incoming resources and application of resources for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustee's use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustee with respect to going concern are described in the relevant sections of this report.

Other information

The Trustee is responsible for the other information. The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information; we are required to report that fact.

We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 require us to report to you if, in our opinion:

- the information given in the Trustee's Annual Report is inconsistent in any material respect with the financial statements; or
- the charity has not kept sufficient accounting records; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of Trustee

As explained more fully in the Trustee's Responsibilities Statement set out on page 17, the Trustee is responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustee determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustee is responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustee either intends to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Auditors' responsibilities for the audit of the financial statements

We have been appointed as auditors under the Charities Act 2011 and report in accordance with regulations made under that Act.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditors' report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The specific procedures for this engagement and the extent to which these are capable of detecting irregularities, including fraud are detailed below.

Identifying and assessing risks related to irregularities:

We assessed the susceptibility of the charity's financial statements to material misstatement and how fraud might occur, including through discussions with the Trustee, discussions within our audit team planning meeting, updating our record of internal controls and ensuring these controls operated as intended. We evaluated possible incentives and opportunities for fraudulent manipulation of the financial statements. We identified laws and regulations that are of significance in the context of the charity by discussions with the Trustee and updating our understanding of the sector in which the charity operates.

Laws and regulations of direct significance in the context of the charity include the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008 and guidance issued by the Charity Commission for England and Wales.

Audit response to risks identified:

We considered the extent of compliance with these laws and regulations as part of our audit procedures on the related financial statement items including a review of financial statement disclosures. We reviewed the charity's records of breaches of laws and regulations, minutes of meetings and correspondence with relevant authorities to identify potential material misstatements arising. We discussed the charity's policies and procedures for compliance with laws and regulations with members of management responsible for compliance.

During the planning meeting with the audit team, the engagement partner drew attention to the key areas which might involve non-compliance with laws and regulations or fraud. We enquired of management whether they were aware of any instances of non-compliance with laws and regulations or knowledge of any actual, suspected or alleged fraud. We addressed the risk of fraud through management override of controls by testing the appropriateness of journal entries and identifying any significant transactions that were unusual or outside the normal course of business. We assessed whether judgements made in making accounting estimates gave rise to a possible indication of management bias. At the completion stage of the audit, the engagement partner's review included ensuring that the team had approached their work with appropriate professional scepticism and thus the capacity to identify non-compliance with laws and regulations and fraud.

There are inherent limitations in the audit procedures described above and the further removed non-compliance with laws and regulations is from the events and transactions reflected in the financial statements, the less likely we would become aware of it. Also, the risk of not detecting a material misstatement due to fraud is higher than the risk of not detecting one resulting from error, as fraud may involve deliberate concealment by, for example, forgery or intentional misrepresentations, or through collusion.

A further description of our responsibilities is available on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charity's Trustee, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the Trustee those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the Trustee as a body, for our audit work, for this report, or for the opinions we have formed.

.....

Saffery LLP
Chartered Accountants and Statutory Auditors
Westpoint, Peterborough Business Park, Lynchwood, Peterborough, PE2 6FZ

Date:

Saffery LLP is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

Statement of financial activities for the year ended 30 September 2023

	Note	Unrestricted funds £000s	Restricted funds £000s	Total funds 2023 £000s	Total funds 2022 £000s
Income from:					
Diageo donations:	3	11,666	-	11,666	15,054
Health Department grants	5	-	13,037	13,037	12,638
Investment income	2	4,886	137	5,023	3,137
Other income		75	-	75	210
Total		16,627	13,174	29,801	31,039
Expenditure on:					
Raising funds (solely investment management fees)	6	(316)	-	(316)	(417)
Charitable activities	6	(54,514)	(13,254)	(67,768)	(33,655)
Total		(54,830)	(13,254)	(68,084)	(34,072)
Net gains/(losses) on investments	9	13,273	-	13,273	(13,793)
Net income (expenditure)		(24,930)	(80)	(25,010)	(16,826)
Reconciliation of funds					
Fund balances brought forward at 1 October 2022/2021	11	157,244	566	157,810	174,636
Fund balances carried forward at 30 September 2023/2022	11	132,314	486	132,800	157,810

All activities are continuing. All gains and losses recognised in the year are included in the Statement of Financial Activities.

Balance Sheet as at 30 September 2023

		Total funds 30/09/2023 £000s	Total funds 30/09/2022 £000s
	Note		
Fixed assets			
Tangible assets	8	443	324
Investments	9	146,616	170,591
		147,059	170,915
Current assets			
Debtors and prepayments	15	108	111
Advance of grants	15		
amounts falling due within one year		214	574
amounts falling due after one year		551	1,046
Cash at bank and in hand		14,281	8,097
		15,154	9,828
Creditors: amounts falling due within one year			
Beneficiary nominee accounts	12	(29,183)	(22,646)
Creditors and accruals	16	(230)	(287)
		(29,413)	(22,933)
Net current assets		(14,259)	(13,105)
Total assets less current liabilities		132,800	157,810
Net assets		132,800	157,810
Trust funds			
General fund	11	128,815	153,642
Beneficiary memorandum accounts	11,12	3,499	3,602
		132,314	157,244
Restricted fund	11	486	566
		132,800	157,810

The financial statements on pages 22 to 41 were approved by the Board on 30 January 2024 and signed on behalf of the Corporate Trustee by:

Mark Spofforth
Director

Mark Benstead
Director

Cash flow statement for the year ended 30 September 2023

	Note	Total funds 2023 £000s	Total funds 2022 £000s
Cash flows from operating activities:			
<i>Net cash provided by (used in) operating activities</i>		<u>(35,941)</u>	<u>(5,026)</u>
Cash flows from investing activities			
Dividends, interest and rents from investments		5,023	3,137
Purchase of tangible fixed assets	8	(159)	(26)
Proceeds from sale of tangible fixed assets		14	15
Purchase of investments	9	(37,591)	(65,401)
Proceeds from sale of investments	9	74,466	67,610
<i>Net cash provided by (used in) investing activities</i>		<u>41,753</u>	<u>5,335</u>
Change in cash and cash equivalents in the reporting period		5,812	308
Cash and cash equivalents as 1 October 2022		9,362	9,054
Cash and cash equivalents as at 30 September 2023		<u>15,174</u>	<u>9,362</u>
Cash held for investment	9	893	1,265
Cash at bank and in hand		14,281	8,097
Cash as at 30 September 2023		<u>15,174</u>	<u>9,362</u>
Reconciliation of income/(expenditure) to net cash (outflow) from operating activities			
<i>Net expenditure for the reporting period as per the statement of financial activities</i>		(25,010)	(16,826)
Adjustments for:			
Depreciation & profit on disposals		26	18
(Gains)/losses on investments		(13,273)	13,793
Dividends, interest and rents from investments		(5,023)	(3,137)
Increase/(decrease) in creditors due within one year		6,480	794
(Increase)/decrease in debtors		859	332
<i>Net cash provided by (used in) operating activities</i>		<u>(35,941)</u>	<u>(5,026)</u>

1. Accounting policies

Basis of preparation

The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued in October 2019 and the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2022 and UK Generally Accepted Practice as it applies from 1 January 2019.

The financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following Accounting and Reporting by Charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued in October 2019 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

The Trust, which is an unincorporated discretionary charitable trust, constitutes a public benefit entity as defined by FRS 102. The sole trustee is the Thalidomide Trust Company, which is an incorporated trustee company. The financial statements have been prepared on a going concern basis (that is to say, that the charity has the resources to continue in operations for a minimum of 12 months from the date of signing these financial statements) and accounting policies have been applied consistently.

The undertaking by Diageo plc in their 2018 Deed of Covenant is to make annual donation payments until 2037, with a commitment thereafter to ensure funding is sufficient to maintain grants for the lifetime of beneficiaries. The Health Grant funding agreements that are in place until April 2023 have been formally extended to a lifetime commitment by England, Scotland and Wales (similar discussions are ongoing with Northern Ireland, however long-term decision-making is currently on hold while there is no functioning National Executive in place there). These agreements support the conclusion that the charity is a going concern.

The financial statements are prepared in sterling, which is the functional currency of the Trust, and rounded to the nearest £000. The date for authorisation of the issue of the financial statements was 30 January 2024.

The Thalidomide Trust has taken advantage of the exemption under section 24.13A of the Charities SORP not to prepare consolidated accounts. The financial statements present information about the Trust as an individual entity and not about its group.

Fund accounting

Unrestricted Funds

Unrestricted funds are expendable at the discretion of the Trustees in the furtherance of the objects of the Thalidomide Trust. The Trust's level of reserves is maintained in order to meet the anticipated future grant allocations.

The General Fund and Beneficiary Memorandum Accounts are derived from funds provided by Diageo plc and its predecessors, and investment returns, as defined in note 12.

Notes to the financial statements for the year ended 30 September 2023 (continued)

1 Accounting policies (continued)

Restricted Funds

Restricted income funds are funds whose use is restricted to specific purposes according to the terms on which the funds were received. Where income is received for purposes specified by the donor that income is shown as restricted in the Statement of Financial Activities. Expenditure for the specified purposes is shown as restricted expenditure. Any unexpended balance at the balance sheet date is carried forward as a restricted income fund.

Restricted Funds are derived from the Health and Social Care Departments in England, Scotland, Wales and Northern Ireland as detailed in note 5.

Tangible fixed assets

The cost of tangible fixed assets is their purchase cost, together with any incidental costs of acquisition. Depreciation is calculated so as to write off the cost of tangible fixed assets on a straight-line basis over the useful economic lives of the assets concerned.

The principal depreciation rates used are as follows:

Motor vehicles	-	25% per annum
Furniture and equipment	-	20% per annum
Buildings	-	2% per annum
Fixtures and fittings	-	14 % per annum

The Trust has a capitalisation threshold of £2,500.

Tangible fixed assets are written down to their realisable value if it is considered there has been a permanent diminution in their value.

Investments

Unquoted unit trust investments are stated at the market value as established by the administrators of the unit trust. Market value is based upon the buying and selling price of the underlying securities in the relevant market with allowances made for cash, accrued income and costs within the unit trust fund.

Derivatives are initially recognised at transaction value and subsequently measured at their settlement value.

Income from investments

Income from investments is recognised when its receipt is probable and the amount receivable can be measured reliably. Any realised and unrealised gains and losses on revaluation or disposals are combined in the statement of financial activities.

1 Accounting policies (continued)

Other incoming resources

Other income consists of fee income charged to beneficiaries, which is recognised upon the issuance of Advances on future grants to beneficiaries. These Advances are intended to assist with major property, mobility and health related purchases. The fee level is based on the cost to the Trust of making the Advances, which includes a contribution towards the loss of income generated by the Trust's cash and investments as a result of withdrawing the cash to be advanced to the beneficiary.

Income from rent

Income from rent is recognised on a straight line basis over the period in which the service is provided.

Diageo donation

The Diageo donation is paid under the terms of a Deed of Covenant dated 23 January 2018 which sets out an undertaking to make annual payments until 2037 and with a commitment thereafter to ensure funding is sufficient to maintain grants for the lifetime of beneficiaries.

The income is recognised when there is evidence of entitlement, receipt is probable and the amount can be measured reliably. For the Diageo donation, this is upon the receipt of the cash.

Income from Health and Social Care Departments

The income is recognised when there is evidence of entitlement, receipt is probable and the amount can be measured reliably. For the Health and Social Care Departments Grants, this is upon the receipt of the cash.

Pension arrangements

The Trust operates a defined contribution pension scheme for employees. Contributions are paid into the group scheme, the assets of which are held in an independently administered fund. Contributions are charged to the statement of financial activities as they become payable. The Trust provides no other post-retirement benefits to its employees.

Charitable expenditure

All charitable expenditure is accounted for on an accruals basis and has been classified under the category headings, which aggregate all costs related to each category, as shown in note 6. Where costs cannot be directly attributed to particular headings they have been allocated in proportion to the time spent by staff on work under each heading.

Grant-making

Grants payable are accounted for in full as liabilities of the charity when approved by the trustees.

Non-financial support costs

Beneficiary support costs comprise the direct costs, including staff, attributable to delivering the Trust's wide range of financial and non-financial support to beneficiaries.

Accounting policies (continued)

Governance

Governance costs cover expenditure on maintaining the constitutional and policymaking framework of the Trust and compliance with statutory requirements.

Irrecoverable VAT

Any irrecoverable VAT is charged to the statement of financial activities, or capitalised as part of the cost of the related asset, where appropriate.

Judgements and key sources of estimation uncertainty

Preparation of the financial statements requires management to make significant judgements and estimates. The items in the financial statements where these judgements and estimates have been made include the recognition of incoming donations and grants, and value of the Advances of Grants amounts falling due within, and after, one year.

The value of incoming grants and donations are agreed on an annual basis with both Diageo plc and the four Health and Social Care Departments in the UK to reflect the level of support needed for current beneficiaries. Future receipts are not anticipated within the financial statements as there is uncertainty as to the level of the receipts.

Advances of Grants are recovered by the Trust through deductions from future grants allocated to beneficiaries. Where possible, the Trust places a charge on property as security for the Advance and has further reduced the risk of the non-repayment of an Advance through a debit balance insurance policy held by the Trust. Based on these actions, in the judgement of the Trust's management the Advances as at the year-end are fully recoverable.

Notes to the financial statements for the year ended 30 September 2023 (continued)

2. Investment income

	2023 £000s	2022 £000s
Unrestricted		
Global Unit Trusts (Equities)	2,641	1,405
Global Unit Trusts (Fixed Income)	1,327	1,035
UK Charity Funds (Equities)	613	694
Directly Held Equities	0	0
Cash Holdings	305	2
	4,886	3,136
Restricted fund		
Cash Holdings	137	1
Total per Statement of Financial Activities	5,023	3,137

3. Diageo plc donation

On 23 January 2018 Diageo plc entered into a Deed of Covenant with the Thalidomide Trust which replaced earlier covenants executed by Guinness plc in 1995 and Diageo plc in 2000, 2005 and 2012.

Under this Covenant future increases in the Annual Grant paid to beneficiaries will be linked to the Retail Price Index (RPI).

4. Investment management fees

The Investment Managers charge a fee for their services based upon an agreed percentage of the market value of the investments under management and a performance related fee.

The Investment Managers' fees charged for the year amounted to £271,000 (2022: £371,000).

In addition to the Investment Managers' fees, Trust costs relating to investment management were £44,000 (2022: £46,000). This is made up of £34,000 of investment consultancy services and £10,000 of staff time.

5 Grant-making

Unrestricted Funds: General Grants

The Trustees' grant-making policy has been:

For beneficiaries with capacity to manage their financial affairs

The Trustees maintain a non-interest bearing nominee account for each beneficiary.

An Annual Grant is paid into the nominee account. A beneficiary has absolute entitlement to the balance in his or her nominee account and the balance is recognised as a liability of the Trust. Beneficiaries can instruct the Trust to make payments up to the balance in their nominee accounts from which they have entire discretion over the amount and frequency of the payments.

The Annual Grant is calculated with reference to the financial position of the Trust and each beneficiary's degree of disability, in accordance with the criteria applicable to distributions set out in the Diageo Deed of Covenant. The Trustees reserve the right to amend the method of calculating the Annual Grant.

In addition to the Annual Grant, the Trustees will consider requests for Major Advances (normally relating to significant one-off costs to meet mobility and housing needs), Short-Term Advances (to enable beneficiaries to make a transition in their housing arrangements where there are complex needs) and Emergency Advances (to meet unanticipated costs in the short term).

Where a Major, Short-Term or Emergency Advance has been made, future Annual Grants will be reduced by the amortisation of the Advance and an agreed annual fee to reflect the costs associated with making the Advance and the reduction in the Trust's investment assets as a result of the Advances. Major Advances will normally result in a reduction to the Annual Grants for a number of years whereas Short-Term and Emergency Advances will normally result in a reduction to the following year's Annual Grant.

In addition, the Trustees have established a small Exceptional Needs Fund which allows beneficiaries with exceptional health and wellbeing needs which cannot reasonably be met from their existing income to apply for an additional one-off grant.

For beneficiaries who lack capacity to manage their financial affairs

The Trustees make payments to meet the needs of the beneficiary following discussion with the beneficiary's deputy or attorney officially registered with the Court of Protection to manage the beneficiary's financial affairs. Once funds have been transferred to the deputy or attorney for the benefit of the beneficiary, control of these funds passes absolutely out of the Trust. However, in line with Trust's policy on beneficiaries who lack capacity, there is a requirement for regular reporting on how these funds are utilised to meet the needs of the beneficiary and professional oversight.

Until such time as beneficiaries who lack capacity have a professional deputy in place, or where the appointed deputy has not fully complied with the regular reporting requirements, their Annual Grants are held in Beneficiary Memorandum Accounts as designated funds.

5 Grant-making (continued)

All payments will always remain at the discretion of the trustees and will be allocated in accordance with the principles set out in the Trust Deed and in line with the Trust's policy on beneficiaries who lack capacity.

	2023		2022	
	Number of beneficiaries	Value of grants £000s	Number of beneficiaries	Value of grants £000s
Beneficiaries with capacity to manage their financial affairs	414	49,207	421	19,321
Beneficiaries who lack capacity to manage their financial affairs	22	3,761	21	1,291
Total of Grants	436	52,968	442	20,612

Restricted Funds: Government Grants

The four UK Health (and Social Care) Departments provide funding for the Health Grants to meet beneficiaries' health and wellbeing needs. The governments of England, Scotland and Wales have made a commitment to lifetime funding of the Health Grant and have renewed the grant agreements for a 4 year period. Discussions with Northern Ireland are ongoing, however a payment was made in 2023.

Health Grant funding is distributed in accordance with the Trust's existing distribution policy. The costs associated with administering the scheme are met from the funding. Details of Health Grant direct and indirect costs are set out in note 6. The level of costs charged has been determined by reference to factors such as the time spent on Health Grant related work (both administering and monitoring /reporting activities).

Trust staff and beneficiary representatives meet with each of the Health and Social Care Departments on an ongoing basis. One of the key objectives of these reviews and the related discussions is to actively manage the level of support requested from the four UK Health and Social Care Departments and the level and nature of the Health Grant fund expenditure such that there are no long term deficits, or surpluses, on the restricted Health Grant funds.

Health Grants by Country

	England	Scotland	Wales	N. Ireland	Total
£000s					£000s
Fund balances as at 1 October 2022	209	283	37	37	566
Incoming Health Grants	9,791	1,547	1,123	576	13,037
Health Grants Allocation	(9,467)	(1,624)	(1,138)	(566)	(12,795)
Interest income	103	16	12	6	137
Health Grant - Direct costs	(52)	(33)	(6)	(3)	(94)
Health Grants – Indirect costs	(286)	(45)	(22)	(12)	(365)
Fund balances as at 30 September 2023	298	144	6	38	486

Notes to the financial statements for the year ended 30 September 2023 (continued)

6 Trust costs and net income

		2023			2022		
	Note	Unrestricted £000s	Restricted £000s	Total £000s	Unrestricted £000s	Restricted £000s	Total £000s
Expenditure on raising funds:							
Investment management fees	4	272	-	272	371	-	371
Support costs (see below)		44	-	44	44	2	46
		316	-	316	415	2	417
Charitable activities:							
Grants	5,12	52,968	12,795	65,762	20,612	11,536	32,149
Net decrease in memorandum account balances	11,12	103	-	103	(349)	-	(349)
		53,071	12,795	65,865	20,263	11,536	31,800
Costs of grant making (see below)		137	33	170	136	36	172
Beneficiary support costs (see below)		1,015	344	1,360	898	290	1,188
Support costs (see below)		291	82	373	403	93	496
		54,514	13,254	67,768	21,700	11,955	33,655

2023								
	Staff and other HR costs	Admin and running costs	Legal, Professional and Audit fees	National Advisory Council	Campaigning Costs	Research & Development	Total	Restricted costs allocation
	£000s	£000s	£000s	£000s	£000s	£000s	£000s	£000s
Expenditure on raising funds:								
Investment management	6	4	34	-	-	-	44	-
Expenditure on charitable activities:								
Costs of grant-making	81	19	38	-	-	-	138	33
Beneficiary support costs	684	304	5	3	-	18	1,015	344
Other costs:								
- Governance & admin	152	38	48	14	-	-	252	
- New claims	18	12	-	-	-	-	30	
- Campaigns	1	-	-	-	7	-	9	
Total other costs	171	51	48	14	7	-	291	82
Total unrestricted costs	942	377	125	17	7	18	1,488	
Restricted costs								
Beneficiary support costs	301	133	26	-	-	-	459	459
- Health Grant recharged								
Total costs – 2023	1,243	510	151	17	7	18	1,947	
Total costs - 2022 (see below)	1,077	596	158	39	13	17	1,901	

Notes to the financial statements for the year ended 30 September 2023 (continued)

6 Trust costs and net income (continued)

Comparative 2022	Staff and other HR costs	Admin and running costs	Legal, Professional and Audit fees	National Advisory Council	Campaigning Costs	Research & Development	Total	Restricted costs allocation
	£000s	£000s	£000s	£000s	£000s	£000s	£000s	£000s
Expenditure on raising funds:								
Investment management	5	1	38	-	-	-	44	2
Expenditure on charitable activities:								
Costs of grant-making	70	29	37	-	-	-	136	36
Beneficiary support costs	599	271	3	8	-	17	898	290
Other costs:								
- Governance & admin	123	144	55	31	-	-	353	
- New claims	19	13	-	-	-	-	32	
- Campaigns	4	-	-	-	13	-	17	
Total other costs	146	157	55	31	13	-	403	93
Total unrestricted costs	820	459	133	39	13	17	1,481	
Restricted costs								
Beneficiary support costs - Health Grant recharged	257	138	25	-	-	-	421	421
Total costs – 2022	1,077	596	158	39	13	17	1,901	

Net income for the year is stated after charging/crediting:

	2023 £000s	2022 £000s
Depreciation	34	25
Audit Fees	32	28
Profit on disposal of fixed assets	(8)	(7)

7 Trustee and employee information

The monthly average number of persons employed by the Trust during the year was 19 (2022: 19).

Staff costs (for the above persons)	2023 £000s	2022 £000s
Gross salaries and wages	854	758
Social security costs	94	87
Employer pension contributions	83	75
Other employee benefits	32	33
	1,063	953

The number of employees whose total emoluments (i.e. salary and taxable benefits) exceeded £60,000 were:

	2023 Number	2022 Number
£60,001 - £70,000	1	1
£70,001 - £80,000	0	1
£80,001 - £90,000	2	1
£110,001 - £120,000	1	1

No remuneration was paid to the Trustees of The Thalidomide Trust Company Ltd (2022: £nil). Travel and subsistence expenses of £7,000 (2022: £6,000) were reimbursed to 5 (2022: 4) Trustees of The Thalidomide Trust Company Ltd during the year.

The total remuneration and benefits received by the Trust's key management personnel was £318,000 (2022: £294,000) for 3 employees (2022: 3).

8 Tangible assets

Tangible assets comprise the following:

	Motor Vehicles	Furniture & equipment	Office Building	Office Refurb	Total
	£000s	£000s	£000s	£000s	£000s
Cost					
At 1 October 2022	54	12	465	-	531
Additions	-	-	-	159	159
Disposals	(28)	-	-	-	(28)
At 30 September 2023	26	12	465	159	662
Accumulated depreciation					
At 1 October 2022	19	3	185	-	207
Charged	11	3	9	11	34
Disposals	(22)	-	-	-	(22)
At 30 September 2023	8	6	194	11	219
Net book value					
At 30 September 2023	18	6	271	148	443
At 30 September 2022	35	9	280	-	324

All tangible fixed assets are unrestricted.

9 Investments

	2023 £000s	2022 £000s
Unlisted investments		
Equities	103,634	143,628
Fixed Income	42,090	25,698
Cash held for investments (including accrued investment income)	893	1,265
Total per Balance Sheet	146,616	170,591

All equities and fixed income are held in Global Unit Trusts.

All investments are held as unrestricted funds.

9 Investments (continued)

The movement on investments in the year was as follows:

	2023 £000s	2022 £000s
Market value b/fwd 1 October 2022	170,591	186,134
Less: Disposal proceeds/ share exchanges	(74,466)	(67,610)
Add: Purchases at cost/share exchanges	37,591	65,401
Realised and unrealised gains/(losses)	13,273	(13,793)
Increase/(decrease) in cash held for investment (including accrued investment income)	(373)	459
Market value at 30 September 2023	146,616	170,591
Historical cost at 30 September 2023	127,061	157,336

Although the Trust's investments have generated positive returns this year, the size of the portfolio has reduce as the additional lump sum payment was paid out of existing reserves.

The Trustees believe that the carrying value of the listed investments is supported by the underlying net assets.

10 Subsidiary

The valiDATE Trust was established on 7 August 2019 as a Private Limited Company by guarantee. The Thalidomide Trust has taken advantage of the exemption under section 24.13A of the Charities SORP, and not consolidated the results of valiDATE Trust in the Group financial statements.

All costs associated with the establishment of the company were incurred by the Trust and recharged to the company.

At the 30 September 2023, valiDATE Trust owed the parent company, The Thalidomide Trust, £38,000 (2022: £35,000).

The results of valiDATE Trust for the period ended 30 September 2023 are shown below. Audited Accounts are filed with the Registrar of Companies.

	2023 £
Turnover and other income	16,320
Cost of sales and expenses	(15,814)
Profit for the year	506
Profit and loss reserves	(14,443)

11 Trust Fund including comparatives

	Unrestricted funds			
	Designated Beneficiary Memorandum Accounts £000s	General Fund £000s	Restricted Fund £000s	Total Trust Funds £000s
Balance as at 1 October 2022	3,602	153,642	566	157,810
Net incoming/(outgoing) resources as per Statement of Financial Activities	-	(24,930)	(80)	(25,010)
Adjustment for net increase in beneficiary memorandum accounts (note 12)	(103)	103	-	-
Balance as at 30 September 2023	3,499	128,815	486	132,800
	Note 12		Note 5	

	Unrestricted funds			
	Designated Beneficiary Memorandum Accounts £000s	General Fund £000s	Restricted Fund £000s	Total Trust Funds £000s
Fixed Assets				
Tangible	-	443	-	443
Investments	2,382	144,234	-	146,616
Current Assets				
Debtors and Prepayments	-	108	7	115
Advance of Grants	-	765	-	765
Cash at Bank and in Hand	1,117	5,540	7,624	14,281
Creditors: amounts falling due within one year				
Beneficiary nominee accounts	-	(22,038)	(7,145)	(29,183)
Creditors and accrued expenses	-	(237)	-	(237)
Balance as at 30 September 2022	3,499	128,815	486	132,800
	Note 12		Note 5	

Notes to the financial statements for the year ended 30 September 2023 (continued)

11 Trust Fund including comparatives (continued)

Comparatives	Unrestricted funds		Restricted Fund £000s	Total Trust Funds £000s
	Beneficiary Memorandum Accounts £000s	General Fund £000s		
Balance as at 1 October 2021	3,253	171,499	(116)	174,636
Net incoming/(outgoing) resources as per Statement of Financial Activities	-	(17,508)	682	(16,826)
Adjustment for net increase in beneficiary memorandum accounts	349	(349)	-	-
Balance as at 30 September 2022	3,602	153,642	566	157,810
	Note 12		Note 5	

Comparatives	Unrestricted funds		Restricted Fund £000s	Total Trust Funds £000s
	Beneficiary memorandum Accounts £000s	General Fund £000s		
Fixed Assets				
Tangible	-	324	-	324
Investments	2,941	167,650	-	170,591
Current Assets				
Debtors and Prepayments	-	111	-	111
Advance of Grants	-	1,620	-	1,620
Cash at Bank and in Hand	661	1,231	6,205	8,097
Creditors: amounts falling due within one year				
Beneficiary nominee accounts	-	(17,007)	(5,639)	(22,646)
Creditors and accrued expenses	-	(287)	-	(287)
Balance as at 30 September 2022	3,602	153,642	566	157,810
	Note 12		Note 5	

12 Beneficiary accounts

	Beneficiary memorandum accounts £000s	Beneficiary nominee accounts £000s	Beneficiary Health Grant accounts £000s	Total 2023 £000s	Total 2022 £000s
As at 1 October 2021					
Balance Sheet- Beneficiary Nominee Accounts		17,007	5,639	22,646	21,908
Balance Sheet- Beneficiary Memorandum Accounts	3,602				
Annual Grant Allocations	676	21,189		21,865	20,613
Lump Sum 2023 Allocations	939	30,164		31,103	-
Health Grant Allocations			12,795	12,795	11,547
Payments from Beneficiary Accounts	(1,718)	(46,322)	(11,289)	(59,329)	(31,073)
Transfers between Nominee and Memorandum Accounts	-	(-)			
Adjustment for net decrease/ (increase) in Beneficiary Memorandum Accounts				103	(349)
As at 30 September 2022:					
Balance Sheet- Beneficiary Nominee Accounts		22,038	7,145	29,183	22,646
Balance Sheet- Beneficiary Memorandum Accounts	3,499				
	Note 11				

Beneficiary Memorandum Accounts are all designated funds and include: accounts for beneficiaries who lack capacity to manage their financial affairs (as detailed at note 5) and lump sum compensation payments allocated to new beneficiaries accepted by the Trust. On the death of a beneficiary, any funds held in Memorandum Accounts revert to the General fund to be used for the benefit of the wider community.

Beneficiary nominee accounts include the grant funds to which a beneficiary has absolute entitlement and which have not been requested by beneficiaries at the year-end (as detailed in note 5).

Beneficiary Health Grant accounts include the Health Grant funding made available, but not requested by beneficiaries (as detailed in note 5). On the death of a beneficiary, any Health Grant funds not yet paid out are repaid to the respective government.

13 Taxation

The Trust is a registered charity, and as such is entitled to certain tax exemptions on income and profits from investments, and surpluses on any trading activities carried on in furtherance of the charity's primary objectives, if these profits and surpluses are applied solely for charitable purposes.

During the current and prior years, all distributions to beneficiaries were paid under the terms of Statutory Instrument 2004 No 1819, which allows distributions from the Trust to be paid free of income tax, and therefore no income tax liability arose.

14 Pension obligations**Defined contribution scheme**

Permanent staff are eligible to receive a pension provision equivalent to 10% of gross salary under a defined contribution scheme. During the year employer contributions to this scheme amounted to £79,000 (2022: £75,000).

At the end of the year other creditors and accruals included £13,000 (2022: £12,000) payable in respect of employer pension contributions.

15 Debtors

	Total funds 2023 £000s	Total funds 2022 £000s
Advances of Grants		
amounts falling due within one year	214	574
amounts falling due after one year	551	1,046
Other debtors	44	35
Prepayments and accrued income	64	76
Total	873	1,731

As set out in note 5, the Trustees will consider requests for Major Advances, Short-Term and Emergency Advances. The current Advances consist of Major Advances and Emergency Advances balances as at 30 September 2023. Advances are recoverable from future Annual Grant allocations. Emergency Advances are recoverable within one year, Major Advances are recoverable up to a maximum of ten years.

16 Creditors

	Total funds 2023 £000s	Total funds 2022 £000s
Creditors: amounts falling due within one year		
Beneficiary nominee accounts (note 12)	29,183	22,646
Other creditors and accruals	230	287
Total	29,413	22,933

Notes to the financial statements for the year ended 30 September 2023 (continued)

17 Net Debt Disclosure

	At 1 October 2022	Cash-flows	Other non- cash changes	At 30 September 2023
	£	£	£	£
Cash	8,097	6,184	-	14,281
Cash held for investment	1,265	(372)	-	893
Total	9,362	5,812	-	15,174

18 Related Party Transactions

Other than expenses paid to Trustees (see note 7), there were no related party transactions during the year.

During the period, the charity made payments for expenditure of its subsidiary, valiDATE Trust of £0 (2022: £2,000).

At the year end, the Trust was owed £38,000 (2022: £35,000) from the valiDATE Trust. This balance is presented within other debtors.

There is no parent undertaking. The ultimate controlling party is The Thalidomide Trust Company Ltd.

19 Comparatives for Statement of Financial Activities

Comparatives		Unrestricted Funds £000s	Restricted Funds £000s	Total Funds 2022 £000s
	Note			
Income from:				
Diageo donations	3	15,054	-	15,054
Health Department Grants	5	-	12,638	12,638
Investment income	2	3,136	1	3,137
Other income		210	-	210
Total		18,400	12,639	31,039
Expenditure on:				
Raising funds (solely investment management fees)	6	(415)	(2)	(417)
Charitable activities	6	(21,700)	(11,955)	(33,655)
Total		(22,115)	(11,957)	(34,072)
Net gains/(losses) on investments	9	(13,793)	-	(13,793)
Net income (expenditure)		(17,508)	682	(16,826)
Reconciliation of Funds				
Fund balances brought forward At 1 October 2021	11	174,752	(116)	174,636
Fund balances carried forward at 30 September 2022	11	157,244	566	157,810

THE THALIDOMIDE TRUST

England & Wales - Charity number 266220

Accounts

The Thalidomide Trust

Annual Report and Financial Statements
for the year ended 30 September 2022

Registered Charity Number 266220

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Reference and administrative details

Registered Name	The Thalidomide Trust
Charity number	266220
Registered address	1 Eaton Court Road Eaton Socon St Neots Cambridgeshire PE19 8ER
Corporate Trustee	The Thalidomide Trust Company (incorporated on 19 January 2018 with Company Number 11160424, registered address as above)

Directors of the Corporate Trustee Company

The Directors of The Thalidomide Trust Company during the year and up to the date of approval were:

Mark Spofforth OBE BSc FCA CTA FRSA (Chair of Trustees)
Sir Robert Nelson QC
Professor Tim Briggs CBE MD(Res) MCh(Ort) FRCS – resigned 16 March 2022
Kevin Wesbroom MA MA FIA – resigned 31 December 2022
Mark Benstead MA MBA
David Body MA Solicitor of Senior Courts of England & Wales
Professor Adrian Charles Newland CBE
Professor William Andrew Owens MD FRCS(CTh)
Professor Rosemary Varley
Ruthe Isden
Shan Abdullah – appointed 1 September 2022
Dame Caroline Swift – appointed 1 January 2023

Senior Management Team	Deborah Jack - Executive Director Katy Sagoe - Director of Health & Wellbeing Suzanne Lluch - Finance Director
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Medical Advisers	Dr Dee Morrison MB ChB Dr Susan Brennan MBChB MRCP Dr Helen Smith MBChB MRCP
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Chair of NAC	Rowland Bareham
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Investment Managers

BlackRock
12 Throgmorton Avenue
London
EC2N 2DL

TwentyFour Asset Management
8th Floor
The Monument Building
11 Monument Street
London EC2R 8AF

Schroders Investment Management Limited
1 London Wall Place
London Wall
London
EC2Y 5AU

Legal & General Investment Management
One Coleman Street
London
EC2R 5AA

Investment Consultants

Hymans Robertson
45 Church Street
Birmingham
B3 2RT

Solicitors

Withers
20 Old Bailey
London
EC4M 7AN

Hewitsons
Shakespeare House
42 Newmarket Road
Cambridge
CB5 8EP

Actuaries

Hymans Robertson
20 Waterloo Street
Glasgow
G2 6DB

Bankers

Lloyds Bank
39 Threadneedle Street
London
EC2R 8AU

Independent auditors

Saffery Champness LLP
Westpoint
Peterborough Business Park
Lynchwood
Peterborough PE2 6FZ

Annual Report

Objectives and activities

The Thalidomide Trust (“the Trust”) was established to provide ‘relief and assistance’ to individuals with disabilities caused by their mothers taking, during pregnancy, a preparation distributed by The Distillers Company (Biochemicals) Limited in the United Kingdom containing the drug known as thalidomide in the late 1950s and early 1960s.

Our aims

All our beneficiaries are now in their late 50s and early 60s and most are feeling the impact of using their bodies in ways for which they were never designed. In addition, as they get older they are experiencing a wide range of age-related health problems that are exacerbated by their original thalidomide damage. This seriously impacts on their quality of life and their ability to remain fully independent. A small number have experienced a cognitive decline alongside the deteriorating physical health and this has resulted in very complex care needs.

The Trust meets the increasingly complex needs of the beneficiary community through the provision of financial support – in the form of annual grant payments – and a range of information, advice and advocacy services. To underpin this, we gather evidence on the needs and experience of our beneficiaries and undertake more detailed research on topics that are of greatest relevance to them.

The Trust has a Vision and five Strategic Goals which were jointly developed – and recently reviewed and updated - by the Trustees, staff and National Advisory Council (NAC) of beneficiary representatives:

Our Vision is that each and every beneficiary of the Trust has access to the resources and support they need to live their best life for the longest time.

Our five strategic goals are.....

- | | |
|----------------|--|
| GOAL 1: | To ensure the Trust’s income is secure, financial risk is effectively managed and adequate funding is available to meet the increasing needs of beneficiaries as they age. |
| GOAL 2: | To apply the Trust’s resources strategically, effectively and equitably (in order to achieve our vision). |
| GOAL 3: | To ensure that all beneficiaries have access to the best possible information, advice, advocacy, services and support – both within and outside the Trust – as they age and their physical and mental health needs increase. |
| GOAL 4: | To ensure effective (two-way) sharing of knowledge and learning for the benefit of the beneficiary community and for wider public benefit. |
| GOAL 5: | To ensure that the individual beneficiary’s needs remain paramount, even when third parties (families, carers, representatives) have a role in acting on their behalf. |

Public Benefit

Although the Trust is very much focussed on the needs of a small, discrete community of beneficiaries, we also take steps to deliver a broader public benefit by sharing our research and learning with other thalidomide organisations around the world and, where relevant, with the broader disability community.

The Trust supports an agreed programme of campaigning activities undertaken by the beneficiary-led Campaigns Team. This is designed to achieve clear agreed outcomes, one of which is increasing public understanding of the thalidomide scandal - to help prevent similar failures occurring - and to highlight the ongoing needs and challenges affecting the Trust's beneficiaries.

The Trust is increasingly aware of the benefit of sharing lessons learned from almost fifty years of supporting this unique community with other groups of individuals living with disabilities and the organisations that support them and is currently exploring ways of doing this.

Structure, Governance and Management

Structure

The Thalidomide Trust was set up in 1973 - originally as the Thalidomide Children's Trust - and is a charitable discretionary Trust registered with the Charity Commission for England and Wales.

With the consent of the Charity Commission, on 29 January 2018 a new company limited by guarantee, The Thalidomide Trust Company (incorporated on 19 January 2018, Company Number 11160424), was appointed as sole Corporate Trustee of the Trust, replacing the individual Trustees. The Corporate Trustee will be referred to in this document as the Trustee.

The Trustees at the date of incorporation became the Directors of the Company. However, although legally Directors, in recognition of the fact that they function as Trustees and operate within the legal frameworks and guidance of the Charity Commission, they continue to be referred to as Trustees. To reflect this, they are referred to as Trustees (as opposed to the Trustee above) throughout this Annual Report.

During 2019/20, we set up a new company limited by guarantee as a subsidiary of the Thalidomide Trust, with the consent of the Charity Commission. The validATE Trust (registered in England and Wales, with company number 12144047) operates on a not-for-profit basis. It was established specifically to oversee the maintenance and development of an online tool to be used by qualified clinicians to screen individuals using detailed medical data in order to assess the likelihood of Thalidomide Embryopathy (TE). This Diagnostic Algorithm for Thalidomide Embryopathy was one of the key outputs of a meeting of international thalidomide experts organised by the World Health Organisation (WHO) and is designed to be used worldwide to ensure consistent diagnosis of TE, based on the latest international evidence.

Trustees (formally Directors of the Trustee Company)

The Trust is governed by a small, skilled Board who bring a wealth of experience and expertise to the charity including medical, legal, research, governance, health and social care policy, financial management and investment.

Trustees are appointed through a structured recruitment process which focusses on the skills required to meet the current and future needs of beneficiaries. The recruitment process is overseen by the Trust's Chair and there is direct beneficiary involvement in all trustee appointments.

The Trust has a well-defined and comprehensive programme of induction for new Trustees and all new Trustees are offered a mentor from within the existing trustee Board.

The Trustees are legally responsible for the overall management and control of the Trust and meet as a full Board at least three times a year. One of these three meetings is an Awayday which enables the Trustees and the Trust's Senior Management Team to spend dedicated time focussing on long term strategic issues.

The Trust has two key Standing Committees - the Health & Wellbeing Committee and the Finance Committee - which met two and four times respectively during this year. Both Committees are attended by representatives from the Trust's National Advisory Council (NAC). The Health & Wellbeing Committee is jointly-chaired by a Trustee and a beneficiary chosen by the NAC.

There are two additional Committees which met on an ad hoc basis during 2021/22. They are:

- Claims Committee, which considers all evidence and makes recommendations to the Board regarding whether applicants should be accepted as new beneficiaries of the Trust.
- Research Committee, which oversees all research involving the Trust and its beneficiaries and commissions and shapes new research projects.

Staff Team

The day to day running of the Trust is delegated to the Executive Director, supported by a small, dedicated and skilled staff team.

The majority of staff are focussed on supporting beneficiaries in relation to their health and wellbeing in order to maximise their independence and quality of life.

Remuneration Policy

The Trustees are responsible for the Trust's remuneration policy as well as agreeing annual pay increases for the staff team. Trustees take account of market conditions and the pay practice of other comparable charities and employers in the geographic area.

National Advisory Council (NAC)

The Trust Deed makes provision for the appointment of a beneficiary National Advisory Council to advise Trustees on a range of issues.

The NAC is currently comprised of 10 beneficiaries who are elected by the beneficiary community to represent their views and needs. Elections are held each February when three members are currently elected for a four-year term of office. The NAC elects a chair

from among the elected members. The Trustees have responsibility for making regulations relating to the election and removal of members of the NAC.

There were two meetings of the NAC during the year, which were attended by Trustees and staff representatives. Agendas for these meetings are circulated to all beneficiaries in advance to enable them to feed in their views. In addition, summary notes and minutes of the meetings are shared with the beneficiary community after the meeting and there is an opportunity for beneficiaries to participate in an interactive discussion, via Zoom, with selected NAC members.

Beneficiary representatives from the NAC attend meetings of the Board, Finance Committee, Health & Wellbeing Committee and Research Committee to represent the views of the beneficiary community to inform the Trust's decision-making.

During the year, the NAC published regular newsletters to keep the beneficiary community informed of its, and the Trust's, activities. They also individually produced an 'annual report' – in both written and video format - highlighting their activities and achievements over the previous 12 months..

NAC representatives attended all Trust events, which provided opportunities for them to meet with the beneficiary community to share information and seek feedback.

Volunteers

A number of beneficiaries generously volunteer their time and expertise to support the Trust and, through it, the broader beneficiary community.

In the last 12 months over 40 beneficiaries volunteered their time in a wide range of roles including: providing (practical and emotional) peer support; hosting virtual discussions/events for beneficiaries; membership of the NAC; sitting as beneficiary representatives on Trust Committees; attending meetings with the four UK Health and Social Care Departments and contributing to various Trust projects.

Beneficiaries

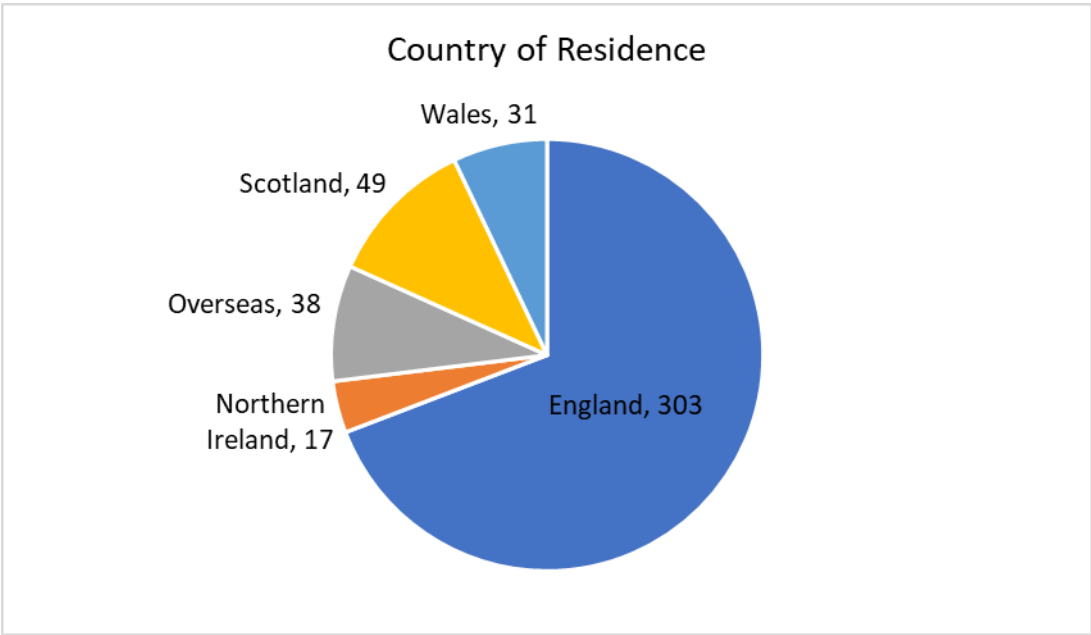
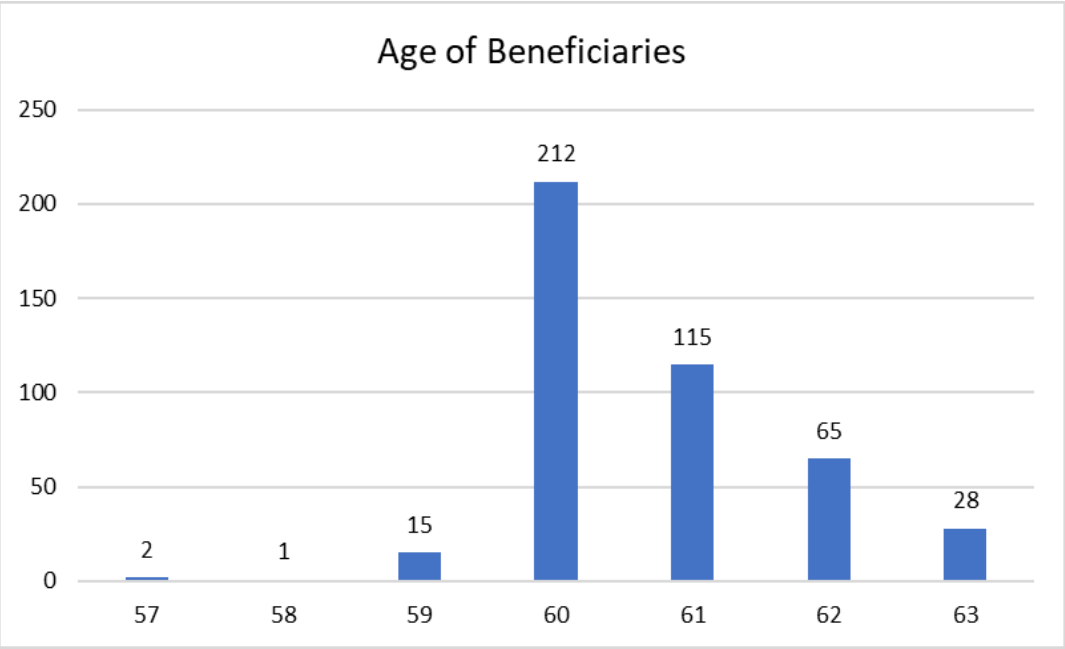
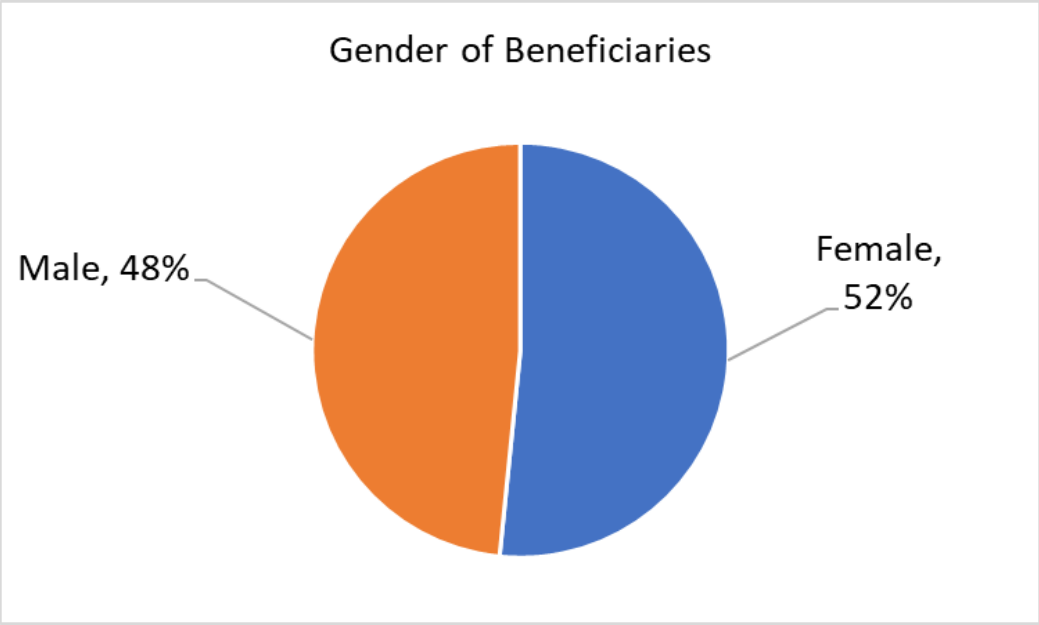
The Trust has responsibility for assessing new applications to become beneficiaries of the Trust and has established a robust procedure for assessing new applications, drawing on international evidence and utilising the diagnostic algorithm, *validATE*, which was one of the key outputs of the WHO conference on Thalidomide Embryopathy held in early 2014.

During the year, the Trust received 31 completed applications from individuals who thought they may be entitled to become beneficiaries. Two individuals were accepted as beneficiaries in the twelve-month reporting period.

It is with regret that the trustees report the deaths of eleven beneficiaries during the year.

At 30 September 2022 there were 438 beneficiaries (2021: 447).

The following charts provide a breakdown of beneficiaries by gender, age and country of residence as at 30 September 2022.



Risk Management

A key role of Trustees is to identify and manage risk and they discharge this duty by means of a Risk Register. The full Risk Register is reviewed by Trustees annually. The most significant risks are reviewed by the Finance Committee on a quarterly basis. This year, the Trustees have satisfied themselves that adequate systems and procedures are in place to manage all of the identified risks.

The principal risks and uncertainties identified by Trustees in their 2022 risk review continued to be the security of future funding and of the Trust's IT systems (including the risk of data security breaches or potential fraud, theft of funds and breaches of beneficiary confidentiality). In addition, continued high levels of inflation, and the impact of this on beneficiaries, was identified as a new risk. Plans to mitigate these risks as far as possible are regularly reviewed and updated by the Trustees.

We continue to review and strengthen our IT security arrangements by improving our data back-up procedures, providing regular cyber security awareness training for staff, Trustees and NAC members and undertaking external penetration testing and phishing simulation campaigns. We have also recently undertaken an external GDPR Review to check that we remain compliant and up to date with our data protection policies and processes.

We have continued to gather robust evidence on the evolving and increasing needs of our beneficiaries and to share this with our funders, together with information on how their funding is improving beneficiaries' quality of life. Our agreements with both Diageo and the four UK Health and Social Care Departments link the level of funding provided each year to inflation measures. In March 2021, the Chancellor of the Exchequer, announced the government's commitment to providing funding for beneficiaries living in England for the rest of their lives and comparable commitments were made by the Scottish and Welsh Governments during 2022. Discussions with the Northern Ireland Government are ongoing.

The Trustees treat safeguarding of our beneficiaries as an important priority and have a robust safeguarding policy in place. Sadly, during the 12-month reporting period, in four cases safeguarding concerns involving family members or carers were identified and reported to external bodies (Local Authority Safeguarding leads and/or the police).

Achievements and Performance

We continue to provide a wide range of ongoing support to our beneficiaries, tailored to meet their individual needs and, as they reach their 60s and experience the usual health issues associated with ageing, their needs are becoming increasingly complex and multi-layered.

Over the 12-month period, 253 individual beneficiaries (over 55% of the beneficiary community) had contact with our Health & Wellbeing Team, many on multiple occasions. The most common issues that beneficiaries require support with are health issues, care and carers, benefits and mental health/emotional support – these issues account for over 80% of contacts with the Health & Wellbeing Team.

In addition to providing day-to-day support, at the start of the year we identified a number of ambitious goals for 2021/22. These are set out below together with an overview of the progress made over the last 12 months:

We said we would...	We ...
... conduct a comprehensive Beneficiary Feedback Survey.	... circulated a feedback survey to all beneficiaries in January 2022, shared the results with both our Trustees and national Advisory Council in May and wrote to all beneficiaries in July with a summary of the findings and told them what action we would be taking in response to these.
.... hold an event for new beneficiaries to encourage them to feel more part of the Trust.	...arranged a small, informal event for new beneficiaries at our offices in St Neots in October 2021 and received overwhelmingly positive feedback from attendees.
...create tailored resources for social care assessors and front-line care staff to increase their understanding of thalidomide damage and the impact it has on daily life.	 are close to finalising the resources for social care assessors and have begun work on the resources for frontline care staff. Both will be completed and go live in 2023.
....undertake a review of our Emergency-card, including feedback from users.	... have recently completed the review and will be discussing the findings with our partner myliferaft in order to identify ways to make it more user-friendly and increase take-up.
.....produce a report of the recently-concluded Upper Limb Research Study.	.. have produced a report and shared it with beneficiaries who participated in the clinic study but are currently unable to circulate it more widely as the research has been submitted for publication to the Lancet.
..... deliver an online event to provide information, advice and guidance to professionals supporting beneficiaries who lack capacity.	.. held an event for professionals supporting our beneficiaries who lack capacity in February 2022 and, on the basis of the positive feedback provided, plan to hold similar events in the future.
.... recruit additional members to our Clinical Network with expertise rehabilitation, pain management and mental health.	... have continued to grow our Clinical Network, including recruiting specialists with expertise in mental health (including trauma), pain management and rehabilitation.

Plans for the Future

In the next 12 months, the Trustees, staff and members of the NAC will continue to work together to implement our new, jointly owned Strategic Plan. Our plans include:

- Securing a commitment to lifetime Health Grant funding from the Northern Ireland government.
- Commissioning research into pain management with a view to developing a new bespoke model of pain management for beneficiaries.
- Refining the data we gather from beneficiaries at Holistic Needs Assessments (HNAs) to deepen our understanding of their future needs.
- Completing and launching new resources for frontline care staff to increase their understanding of thalidomide damage and the impact it has on daily life.
- Undertaking an independent review of our governance arrangements.
- Developing a network of mental health specialists who understand the issues experienced by beneficiaries, including trauma.

Financial Review

During the year the Trust allocated grants totalling £32.1m (2021: £30.4m) to its beneficiaries. The Trust received donations from Diageo plc totalling £15.1m (2021: £13.3m).

Health Grant funding from the four Health and Social Care Departments of the United Kingdom totalled £12.6m (2021: £11.6m). As Health Grant funding is provided for specific, agreed health and wellbeing purposes, these are accounted for by the Trust as funds restricted for these purposes.

The Trust is committed to managing its resources effectively and achieving value for money. It operates a robust budget management system which involves regular review of activity and expenditure by budget holders, oversight by the Management Team and regular reporting of variances to the Trust's Finance Committee. The Trust does not actively fundraise and 100% of its resources are utilised for charitable purposes, including charity governance. During 2021/22, 93% of outgoing resources were in the form of Grants to our beneficiaries. Of the remaining 7% of expenditure, 73% (excluding investment management fees) was spent on providing health and wellbeing support and financial guidance directly to our beneficiaries by our staff and volunteers. The balance of resources was utilised to administer beneficiary Grants, assess new claims, ensure effective governance of the Trust, and deliver agreed campaigning activities.

Investment Objectives

The principal objective of the investment policy is to generate sufficient income and capital return to enable the Trustees to pay Annual Grants for the entire lives of the beneficiaries.

The environmental, social and governance (ESG) nature of Trust investments has been considered at length by the Trustees. The Trustees believe that ESG-related risks, including climate change risks, are financially material and an important component of investment risk. The Trustees believe that organisations that soundly manage ESG-related risks are more likely to be financially sustainable over time, and therefore deliver better long-term risk-adjusted returns. Trustees currently hold £34.7m of funds in an ESG fund with Legal & General Investment Management (LGIM).

As all of the Trust investments are held within pooled funds, the decisions regarding the selection of investments is entrusted to the investment managers, who each act within agreed guidelines. Trustees regularly ask investment managers to explain how ESG factors are incorporated into their decisions regarding the selection of investments.

In line with the 2018 Covenant with Diageo, the Trustees adopted an investment policy which will reduce the investment risk of the portfolio over the lifetime of the Trust.

In order to achieve this, from 2017 to 2022 the Trustees will continue to try to achieve higher returns with a given amount of risk, managed through diversification and active management of the investment assets. From 2022 to 2037 trustees expect to smoothly reduce the investment risk of the portfolio.

The current benchmark against which performance between 2017 and 2022 is represented by a portfolio comprising of 75% global equities and 25% bonds.

Investment Strategy and Performance

The investment strategy is currently implemented through a combination of investments and managers as set out in the table below, together with the ranges within which the policy is managed, in line with the Statement of Investment Principles dated December 2020.

Portfolio	Manager	Central Allocation (% of Assets)	Target Ranges (% of Assets)
Active Global Equities	Schroders	33.5	20-40
Passive Global Equities	BlackRock and LGIM	50.7	40-60
Bond Portfolios	BlackRock and 24AM	15.1	10-30
Cash	Lloyds and RLAM	0.7	0-20

Cash deposits are held with a variety of banks and investment managers.

The total annual return on the Trust's investments for the year was -5.8% (2021: 29.4%) which is higher than the benchmark of -6.2%. This negative return has been due to the impact on the global markets of soaring inflation and higher borrowing costs.

Over the last three years the average rate of return has been 4.8% pa, which is slightly higher than the benchmark of 4.3%.

Significant Investments

At the year end, the following investments represented 5% or more of the total market value of investments:

	£000s	%
Schroders Global Recovery Fund	43,103	25
Legal and General Future World ESG Fund	34,742	20
BlackRock North America	34,033	20
Schroders Charity Equity Fund	13,973	8
BlackRock Fixed Income Global Opportunities Fund	13,315	8
Vontobel –24AM Strategic Income Fund	12,383	7

Derivative Instruments

The Trustees have authorised Schroders to use financial contracts, known as derivatives, to help manage investment portfolio risk. At the year end the open derivatives position was a net liability of £0 (note 9) (2021: £0).

Diageo Covenant

A Deed of Covenant is in place, signed by the Trustees and Diageo plc (successor to The Distillers Company), which sets out Diageo's commitment to long-term support for Thalidomide Trust beneficiaries and to underwrite the investment policy of the Trust. The Covenant enables the Thalidomide Trust both to maintain the programme of Annual Grants to its beneficiaries and deliver ongoing support in response to their evolving and growing health and wellbeing needs.

The Deed of Covenant is reviewed by the Trustees, the NAC and Diageo periodically. In January 2018, an updated Deed of Covenant was agreed which reflects an increased level of support from Diageo.

Government Health Grants

In addition to the assets held by the Trust and the income from Diageo, the UK government supports the Trust by way of Health Grant funding agreements in place with the four UK Health and Social Care Departments since 2009. This money has helped beneficiaries to respond to their growing needs as they age – in order to maximise their independence and quality of life, minimise further deterioration and improve their overall health and wellbeing. The existing 10 year Health Grant agreements come to an end in 2023 (with the last grant payments made to beneficiaries in June 2022). In March 2021, the Chancellor, Rishi Sunak, announced a commitment to lifetime funding of the Health Grant to beneficiaries living in England and during 2022 both Wales and Scotland announced the same commitment. Discussions are still underway with the Northern Ireland government over a similar renewal commitment for beneficiaries living in Northern Ireland but the absence of a National Executive has impeded progress.

Grant Making and Reserves Policy

Beneficiaries receive an Annual Grant, based on their level of disability, from funds that come from Diageo each year in line with the Covenant and the Trust's reserves, including the interest and investment growth accrued.

The Trustees' distribution policy continues to provide individual Annual Grants to beneficiaries for the whole of their lives. The Trustees have to set a policy which will ensure reserves are not depleted whilst beneficiaries are in need of funding, whilst at the same time ensuring all assets are utilised by the time of the death of the last beneficiary. The total unrestricted funds at 30 September 2022 stood at £157m (2021: £175m) whereas the Restricted Fund had a balance of £0.5m at the year-end (2021: -£0.1m).

Statement of the Corporate Trustee's Responsibilities

The Trustee is responsible for preparing the Trustee's Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England and Wales requires the Trustee to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and their application for that period.

In preparing these financial statements, the Trustee is required to:

- select suitable accounting policies and then apply them consistently
- observe the methods and principles in the Charities SORP (Statement of Recommended Practice)
- make judgments and estimates that are reasonable and prudent
- state whether applicable accounting standards, comprising FRS 102, have been followed, subject to any material departures disclosed and explained in the financial statements; and

- prepare the financial statements on the going concern basis¹ unless it is inappropriate to presume that the charity will continue in business.

The Trustee is responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable it to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. The Trustee is also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustee is responsible for the maintenance and integrity of the charity and financial information included on the charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Signed on behalf of the Corporate Trustee:

Mark Spofforth
Chair of the Board of the Thalidomide Trust Company
25 January 2023

¹ The going concern basis means that the charity has the resources to continue in operations for a minimum of 12 months from the date of signing these financial statements

Independent auditors' report to the trustee of The Thalidomide Trust

Report on the audit of the financial statements

Opinion

We have audited the financial statements of The Thalidomide Trust for the year ended 30 September 2022 which comprise the balance sheet as at 30 September 2022; the statement of financial activities for the year then ended; cashflow statement for the year and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102, the Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 30 September 2022 and of its incoming resources and application of resources for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustee's use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustee with respect to going concern are described in the relevant sections of this report.

Other information

The Trustee is responsible for the other information. The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information; we are required to report that fact.

We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 require us to report to you if, in our opinion:

- the information given in the Trustee's Annual Report is inconsistent in any material respect with the financial statements; or
- the charity has not kept sufficient accounting records; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of Trustee

As explained more fully in the Trustee's Responsibilities Statement set out on page 15, the Trustee is responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustee determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustee is responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustee either intends to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Auditors' responsibilities for the audit of the financial statements

We have been appointed as auditors under the Charities Act 2011 and report in accordance with regulations made under that Act.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditors' report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The specific procedures for this engagement and the extent to which these are capable of detecting irregularities, including fraud are detailed below.

Identifying and assessing risks related to irregularities:

We assessed the susceptibility of the charity's financial statements to material misstatement and how fraud might occur, including through discussions with the Trustee, discussions within our audit team planning meeting, updating our record of internal controls and ensuring these controls operated as intended. We evaluated possible incentives and opportunities for fraudulent manipulation of the financial statements. We identified laws and regulations that are of significance in the context of the charity by discussions with the Trustee and updating our understanding of the sector in which the charity operates.

Laws and regulations of direct significance in the context of the charity include the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008 and guidance issued by the Charity Commission for England and Wales.

Audit response to risks identified:

We considered the extent of compliance with these laws and regulations as part of our audit procedures on the related financial statement items including a review of financial statement disclosures. We reviewed the charity's records of breaches of laws and regulations, minutes of meetings and correspondence with relevant authorities to identify potential material misstatements arising. We discussed the charity's policies and procedures for compliance with laws and regulations with members of management responsible for compliance.

During the planning meeting with the audit team, the engagement partner drew attention to the key areas which might involve non-compliance with laws and regulations or fraud. We enquired of management whether they were aware of any instances of non-compliance with laws and regulations or knowledge of any actual, suspected or alleged fraud. We addressed the risk of fraud through management override of controls by testing the appropriateness of journal entries and identifying any significant transactions that were unusual or outside the normal course of business. We assessed whether judgements made in making accounting estimates gave rise to a possible indication of management bias. At the completion stage of the audit, the engagement partner's review included ensuring that the team had approached their work with appropriate professional scepticism and thus the capacity to identify non-compliance with laws and regulations and fraud.

There are inherent limitations in the audit procedures described above and the further removed non-compliance with laws and regulations is from the events and transactions reflected in the financial statements, the less likely we would become aware of it. Also, the risk of not detecting a material misstatement due to fraud is higher than the risk of not detecting one resulting from error, as fraud may involve deliberate concealment by, for example, forgery or intentional misrepresentations, or through collusion.

A further description of our responsibilities is available on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charity's Trustee, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the Trustee those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the Trustee as a body, for our audit work, for this report, or for the opinions we have formed.

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Saffery Champness LLP
Chartered Accountants and Statutory Auditors
Westpoint, Peterborough Business Park, Lynchwood, Peterborough, PE2 6FZ

Date:

Saffery Champness LLP is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

Statement of financial activities for the year ended 30 September 2022

	Note	Unrestricted funds £000s	Restricted funds £000s	Total funds 2022 £000s	Total funds 2021 £000s
Income from:					
Diageo donations	3	15,054	-	15,054	13,338
Health Department grants	5	-	12,638	12,638	11,601
Investment income	2	3,136	1	3,137	2,166
Other income		210	-	210	90
Total		18,400	12,639	31,039	27,195
Expenditure on:					
Raising funds (solely investment management fees)	6	(415)	(2)	(417)	(447)
Charitable activities	6	(21,700)	(11,955)	(33,655)	(32,407)
Total		(22,115)	(11,957)	(34,072)	(32,854)
Net gains/(losses) on investments	9	(13,793)	-	(13,793)	39,506
Net income (expenditure)		(17,508)	682	(16,826)	33,847
Reconciliation of funds					
Fund balances brought forward at 1 October 2021/2020	11	174,752	(116)	174,636	140,789
Fund balances carried forward at 30 September 2022/2021	11	157,244	566	157,810	174,636

All activities are continuing. All gains and losses recognised in the year are included in the Statement of Financial Activities.

Balance Sheet as at 30 September 2022

		Total funds 30/09/2022 £000s	Total funds 30/09/2021 £000s
	Note		
Fixed assets			
Tangible assets	8	324	330
Investments	9	170,591	186,134
		170,915	186,464
Current assets			
Debtors and prepayments	15	111	100
Advance of grants	15		
amounts falling due within one year		574	625
amounts falling due after one year		1,046	1,338
Cash at bank and in hand		8,097	8,248
		9,828	10,311
Creditors: amounts falling due within one year			
Beneficiary nominee accounts	12	(22,646)	(21,908)
Creditors and accruals	16	(287)	(231)
		(22,933)	(22,139)
Net current assets		(13,105)	(11,828)
Total assets less current liabilities		157,810	174,636
Net assets		157,810	174,636
Trust funds			
General fund	11	153,642	171,499
Beneficiary memorandum accounts	11,12	3,602	3,253
		157,244	174,752
Restricted fund	11	566	(116)
		157,810	174,636

The financial statements on pages 21 to 40 were approved by the Board on 25 January 2023 and signed on behalf of the Corporate Trustee by:

Mark Spofforth
Director

Mark Benstead
Director

Cash flow statement for the year ended 30 September 2022

	Note	Total funds 2022 £000s	Total funds 2021 £000s
Cash flows from operating activities:			
<i>Net cash provided by (used in) operating activities</i>		(5,026)	(5,073)
Cash flows from investing activities			
Dividends, interest and rents from investments		3,137	2,166
Purchase of tangible fixed assets	8	(26)	(12)
Proceeds from sale of tangible fixed assets		15	-
Purchase of investments	9	(65,401)	(40,954)
Proceeds from sale of investments	9	67,610	45,463
<i>Net cash provided by (used in) investing activities</i>		5,335	6,663
Change in cash and cash equivalents in the reporting period		308	1,590
Cash and cash equivalents as 1 October 2021		9,054	7,464
Cash and cash equivalents as at 30 September 2022		9,362	9,054
Cash held for investment	9	1,265	806
Cash at bank and in hand		8,097	8,248
Cash as at 30 September 2022		9,362	9,054
Reconciliation of income/(expenditure) to net cash (outflow) from operating activities			
<i>Net income/(expenditure) for the reporting period as per the statement of financial activities</i>		(16,826)	33,847
Adjustments for:			
Depreciation & profit on disposals		18	24
(Gains)/losses on investments		13,793	(39,506)
Dividends, interest and rents from investments		(3,137)	(2,166)
Increase/(decrease) in creditors due within one year		794	2,316
(Increase)/decrease in debtors		332	412
<i>Net cash provided by (used in) operating activities</i>		(5,026)	(5,073)

1. Accounting policies

Basis of preparation

The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 and the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2011 and UK Generally Accepted Practice as it applies from 1 January 2015.

The financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following Accounting and Reporting by Charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

The Trust, which is an unincorporated discretionary charitable trust, constitutes a public benefit entity as defined by FRS 102. The sole trustee is the Thalidomide Trust Company, which is an incorporated trustee company. The financial statements have been prepared on a going concern basis (that is to say, that the charity has the resources to continue in operations for a minimum of 12 months from the date of signing these financial statements) and accounting policies have been applied consistently.

The undertaking by Diageo plc in their 2018 Deed of Covenant is to make annual donation payments until 2037, with a commitment thereafter to ensure funding is sufficient to maintain grants for the lifetime of beneficiaries. The Health Grant funding agreements that are in place until April 2023 have been formally extended to a lifetime commitment by England, Scotland and Wales (similar discussions are ongoing with Northern Ireland, however long-term decision-making is currently on hold while there is no functioning National Executive in place there). These agreements support the conclusion that the charity is a going concern.

The financial statements are prepared in sterling, which is the functional currency of the Trust, and rounded to the nearest £000. The date for authorisation of the issue of the financial statements was 25 January 2023.

The Thalidomide Trust has taken advantage of the exemption under section 24.13A of the Charities SORP not to prepare consolidated accounts. The financial statements present information about the Trust as an individual entity and not about its group.

Fund accounting

Unrestricted Funds

Unrestricted funds are expendable at the discretion of the Trustees in the furtherance of the objects of the Thalidomide Trust. The Trust's level of reserves is maintained in order to meet the anticipated future grant allocations.

The General Fund and Beneficiary Memorandum Accounts are derived from funds provided by Diageo plc and its predecessors, and investment returns.

Notes to the financial statements for the year ended 30 September 2022 (continued)

1 Accounting policies (continued)

Restricted Funds

Restricted income funds are funds whose use is restricted to specific purposes according to the terms on which the funds were received. Where income is received for purposes specified by the donor that income is shown as restricted in the Statement of Financial Activities. Expenditure for the specified purposes is shown as restricted expenditure. Any unexpended balance at the balance sheet date is carried forward as a restricted income fund.

Restricted Funds are derived from the Health and Social Care Departments in England, Scotland, Wales and Northern Ireland as detailed in note 5.

Tangible fixed assets

As an unincorporated association, the Trust was not able to hold property in its own name and so in prior years the property was held in the names of the individual trustees. In January 2018, following the establishment of the sole corporate trustee, the Thalidomide Trust Company, title for the property transferred to the Thalidomide Trust Company, which is an incorporated trustee company. Beneficial ownership, and in substance control, remains with the Trust and the building is therefore disclosed in the financial statements of the Trust.

The cost of tangible fixed assets is their purchase cost, together with any incidental costs of acquisition. Depreciation is calculated so as to write off the cost of tangible fixed assets on a straight-line basis over the useful economic lives of the assets concerned.

The principal depreciation rates used are as follows:

Motor vehicles	-	25% per annum
Furniture and equipment	-	20% per annum
Buildings	-	2% per annum

The Trust has a capitalisation threshold of £2,500.

Tangible fixed assets are written down to their realisable value if it is considered there has been a permanent diminution in their value.

Investments

Unquoted unit trust investments are stated at the market value as established by the administrators of the unit trust. Market value is based upon the buying and selling price of the underlying securities in the relevant market with allowances made for cash, accrued income and costs within the unit trust fund.

Derivatives are initially recognised at transaction value and subsequently measured at their settlement value.

1 Accounting policies (continued)

Income from investments

Income from investments is recognised when its receipt is probable and the amount receivable can be measured reliably. Any realised and unrealised gains and losses on revaluation or disposals are combined in the statement of financial activities.

Other incoming resources

Other income consists of fee income charged to beneficiaries, which is recognised upon the issuance of Advances on future grants to beneficiaries. These Advances are intended to assist with major property, mobility and health related purchases. The fee level is based on the cost to the Trust of making the Advances, which includes a contribution towards the loss of income generated by the Trust's cash and investments as a result of withdrawing the cash to be advanced to the beneficiary.

Income from rent

Income from rent is recognised on a straight line basis over the period in which the service is provided.

Diageo donation

The Diageo donation is paid under the terms of a Deed of Covenant dated 23 January 2018 which sets out an undertaking to make annual payments until 2037 and with a commitment thereafter to ensure funding is sufficient to maintain grants for the lifetime of beneficiaries.

The income is recognised when there is evidence of entitlement, receipt is probable and the amount can be measured reliably. For the Diageo donation, this is upon the receipt of the cash.

Income from Health and Social Care Departments

The UK Government supports the Trust by way of Health Grant funding agreements in place with the Health and Social Care Departments in England, Scotland, Wales and Northern Ireland up until 2022. In March 2021, the Chancellor, Rishi Sunak, announced a commitment to lifetime funding of the Health Grant to beneficiaries living in England. During the year 2022, the governments of Wales and Scotland also announced a lifetime commitment to the beneficiaries residing in those countries. Discussions with the Northern Ireland government regarding the lifetime commitment of Health Grant funding are ongoing.

The income is recognised when there is evidence of entitlement, receipt is probable and the amount can be measured reliably. For the Health and Social Care Departments Grants, this is upon the receipt of the cash.

Pension arrangements

The Trust operates a defined contribution pension scheme for employees. Contributions are paid into the group scheme, the assets of which are held in an independently administered fund. Contributions are charged to the statement of financial activities as they become payable. The Trust provides no other post-retirement benefits to its employees.

Notes to the financial statements for the year ended 30 September 2022 (continued)

Accounting policies (continued)

Charitable expenditure

All charitable expenditure is accounted for on an accruals basis and has been classified under the category headings, which aggregate all costs related to each category, as shown in note 6. Where costs cannot be directly attributed to particular headings they have been allocated in proportion to the time spent by staff on work under each heading.

Grant-making

Grants payable are accounted for in full as liabilities of the charity when approved by the trustees.

Non-financial support costs

Beneficiary support costs comprise the direct costs, including staff, attributable to delivering the Trust's wide range of financial and non-financial support to beneficiaries.

Governance

Governance costs cover expenditure on maintaining the constitutional and policymaking framework of the Trust and compliance with statutory requirements.

Irrecoverable VAT

Any irrecoverable VAT is charged to the statement of financial activities, or capitalised as part of the cost of the related asset, where appropriate.

Judgements and key sources of estimation uncertainty

Preparation of the financial statements requires management to make significant judgements and estimates. The items in the financial statements where these judgements and estimates have been made include the recognition of incoming donations and grants, and value of the Advances of Grants amounts falling due within, and after, one year.

The value of incoming grants and donations are agreed on an annual basis with both Diageo plc and the four Health and Social Care Departments in the UK to reflect the level of support needed for current beneficiaries. Future receipts are not anticipated within the financial statements as there is uncertainty as to the level of the receipts.

Advances of Grants are recovered by the Trust through deductions from future grants allocated to beneficiaries. Where possible, the Trust places a charge on property as security for the Advance and has further reduced the risk of the non-repayment of an Advance through an insurance policy held by the Trust. Based on these actions, in the judgement of the Trust's management the Advances as at the year-end are fully recoverable.

Notes to the financial statements for the year ended 30 September 2022 (continued)

2. Investment income

	2022 £000s	2021 £000s
Unrestricted		
Global Unit Trusts (Equities)	1,405	694
Global Unit Trusts (Fixed Income)	1,035	1,006
UK Charity Funds (Equities)	694	438
Directly Held Equities	0	26
Cash Holdings	2	1
	3,136	2,165
Restricted fund		
Cash Holdings	1	1
Total per Statement of Financial Activities	3,137	2,166

3. Diageo plc donation

On 23 January 2018 Diageo plc entered into a Deed of Covenant with the Thalidomide Trust which replaced earlier covenants executed by Guinness plc in 1995 and Diageo plc in 2000 and 2005 and 2012.

Under this Covenant future increases in the Annual Grant paid to beneficiaries will be in line with the Retail Price Index (RPI.)

4. Investment management fees

The Investment Managers charge a fee for their services based upon an agreed percentage of the market value of the investments under management and a performance related fee.

The Investment Managers' fees charged for the year amounted to £371,000 (2021: £392,000).

In addition to the Investment Managers' fees, Trust costs relating to investment management were £46,000 (2021: £55,000), which comprised of unrestricted costs of £44,000 and restricted costs of £2,000. This is made up of £38,000 of investment consultancy services and £8,000 of staff time.

5 Grant-making

Unrestricted Funds: General Grants

The trustees' grant-making policy has been:

For beneficiaries with capacity to manage their financial affairs

The trustees maintain a non-interest bearing nominee account for each beneficiary.

An Annual Grant is paid into the nominee account. A beneficiary has absolute entitlement to the balance in his or her nominee account and the balance is recognised as a liability of the Trust. Beneficiaries can instruct the Trust to make payments up to the balance in their nominee accounts from which they have entire discretion over the amount and frequency of the payments.

The Annual Grant is calculated with reference to the financial position of the Trust and each beneficiary's degree of disability, in accordance with the criteria applicable to distributions set out in the Diageo Deed of Covenant. The trustees reserve the right to amend the method of calculating the Annual Grant.

In addition to the Annual Grant, the trustees will consider requests for Major Advances (normally relating to significant one-off costs to meet mobility and housing needs), Short-Term Advances (to enable beneficiaries to make a transition in their housing arrangements where there are complex needs) and Emergency Advances (to meet unanticipated costs in the short term).

Where a Major, Short-Term or Emergency Advance has been made, future Annual Grants will be reduced by the amortisation of the Advance and an agreed annual fee to reflect the costs associated with making the Advance and the reduction in the Trust's investment assets as a result of the Advances. Major Advances will normally result in a reduction to the Annual Grants for a number of years whereas Short-Term and Emergency Advances will normally result in a reduction to the following year's Annual Grant.

In addition, the Trustees have established a small Exceptional Needs Fund which allows beneficiaries with exceptional health and wellbeing needs which cannot reasonably met from their existing income to apply for an additional one-off grant.

For beneficiaries who lack capacity to manage their financial affairs

The trustees make payments to meet the needs of the beneficiary following discussion with the beneficiary's deputy or attorney officially registered with the Court of Protection to manage the beneficiary's financial affairs. Once funds have been transferred to the deputy or attorney for the benefit of the beneficiary, control of these funds passes absolutely out of the Trust. However, in line with Trust's policy on beneficiaries who lack capacity, there is a requirement for regular reporting on how these funds are utilised to meet the needs of the beneficiary and professional oversight.

Until such time as beneficiaries who lack capacity have a professional deputy in place, or where the appointed deputy has not fully complied with the regular reporting requirements, their Annual Grants are held in Beneficiary Memorandum Accounts as designated funds.

5 Grant-making (continued)

All payments will always remain at the discretion of the trustees and will be allocated in accordance with the principles set out in the Trust Deed and in line with the Trust's policy on beneficiaries who lack capacity.

	2022		2021	
	Number of beneficiaries	Value of grants £000s	Number of beneficiaries	Value of grants £000s
Beneficiaries with capacity to manage their financial affairs	421	19,321	437	18,337
Beneficiaries who lack capacity to manage their financial affairs	21	1,291	13	907
Total of Grants	442	20,612	450	19,244

Restricted Funds: Departments of Health and Social Care Grants

The four UK Health and Social Care Departments provide funding for the Health Grants under an agreement for the period 2013 to 2022. A commitment to lifetime funding of the Health Grant has been announced by the governments in England, Scotland and Wales, and discussions with Northern Ireland are ongoing.

Health Grant funding is distributed in accordance with the Trust's existing distribution policy. The costs associated with administering the scheme are met from the funding. Details of Health Grant direct and indirect costs are set out in note 6. The level of costs charged has been determined by reference to factors such as the time spent on Health Grant related work (both administering and monitoring /reporting activities).

Trust staff and beneficiary representatives meet with each of the Health and Social Care Departments on an ongoing basis. One of the key objectives of these reviews and the related negotiations is to actively manage the level of support requested from the four UK Health and Social Care Departments and the level and nature of the Health Grant fund expenditure such that there are no long term deficits, or surpluses, on the restricted Health Grant funds.

Health Grants by Country

	England	Scotland	Wales	N. Ireland	Total
£000s					£000s
Fund balances as at 1 October 2021	175	72	(319)	(44)	(116)
Incoming Health Grants	9,080	1,684	1,237	637	12,638
Health Grants Allocation	(8,736)	(1,400)	(858)	(542)	(11,536)
Interest income	1	-	-	-	1
Health Grant - Direct costs	(47)	(31)	(3)	(3)	(84)
Health Grants – Indirect costs	(264)	(42)	(20)	(11)	(337)
Fund balances as at 30 September 2022	209	283	37	37	566

Notes to the financial statements for the year ended 30 September 2022 (continued)

6 Trust costs and net income

		2022			2021		
	Note	Unrestricted £000s	Restricted £000s	Total £000s	Unrestricted £000s	Restricted £000s	Total £000s
Expenditure on raising funds:							
Investment management fees	4	371	-	371	392	-	392
Support costs (see below)		44	2	46	52	3	55
		415	2	417	444	3	447
Charitable activities:							
Grants	5,12	20,612	11,536	32,149	19,244	11,112	30,356
Net decrease in memorandum account balances	11,12	(349)	-	(349)	549	-	549
		20,263	11,536	31,800	19,793	11,112	30,905
Costs of grant making (see below)		136	36	172	94	32	126
Beneficiary support costs (see below)		898	290	1,188	736	327	1,063
Support costs (see below)		403	93	496	242	71	313
		21,700	11,955	33,655	20,865	11,542	32,407

2022	Staff and other HR costs	Admin and running costs	Legal, Professional and Audit fees	National Advisory Council	Campaigning Costs	Research & Development	Total	Restricted costs allocation
	£000s	£000s	£000s	£000s	£000s	£000s	£000s	£000s
Expenditure on raising funds:								
Investment management	5	1	38	-	-	-	44	2
Expenditure on charitable activities:								
Costs of grant-making	70	29	37	-	-	-	136	36
Beneficiary support costs	599	271	3	8	-	17	898	290
Other costs:								
- Governance & admin	123	144	55	31	-	-	353	
- New claims	19	13	-	-	-	-	32	
- Campaigns	4	-	-	-	13	-	17	
Total other costs	146	157	55	31	13	-	403	93
Total unrestricted costs	820	459	133	39	13	17	1481	
Restricted costs								
Beneficiary support costs	257	138	25	-	-	-	421	421
- Health Grant recharged								
Total costs – 2022	1077	596	158	39	13	17	1,901	
Total costs - 2021 (see below)	994	386	93	29	2	51	1,555	

Notes to the financial statements for the year ended 30 September 2022 (continued)

6 Trust costs and net income (continued)

Comparative 2021	Staff and other HR costs	Admin and running costs	Legal, Professional and Audit fees	National Advisory Council	Campaigning Costs	Research & Development	Total	Restricted costs allocation
	£000s	£000s	£000s	£000s	£000s	£000s	£000s	£000s
Expenditure on raising funds:								
Investment management	5	8	38	-	-	-	52	3
Expenditure on charitable activities:								
Costs of grant-making	66	14	14	-	-	-	94	32
Beneficiary support costs	507	172	1	6	-	51	737	324
Other costs:								
- Governance & admin	131	24	23	23	-	-	201	
- New claims	27	9	-	-	-	-	36	
- Campaigns	3	-	-	-	2	-	5	
Total other costs	160	33	23	23	2	-	242	72
Total unrestricted costs	739	227	76	29	2	51	1124	
Restricted costs								
Beneficiary support costs - Health Grant recharged	255	159	17	-	-	-	431	431
Total costs - 2021	994	386	93	29	2	51	1,555	
Total costs - 2020	943	267	53	22	23	140	1,448	

Net income for the year is stated after charging/crediting:

	2022 £000s	2021 £000s
Depreciation	25	24
Audit Fees	28	26
Profit on disposal of fixed assets	(7)	-

7 Trustee and employee information

The monthly average number of persons employed by the Trust during the year was 19 (2021: 18).

Staff costs (for the above persons)	2022 £000s	2021 £000s
Gross salaries and wages	758	720
Social security costs	87	78
Employer pension contributions	75	70
Other employee benefits	33	32
	953	900

The number of employees whose total emoluments (i.e. salary and taxable benefits) exceeded £60,000 were:

	2022 Number	2021 Number
£60,001 - £70,000	1	1
£70,001 - £80,000	1	1
£80,001 - £90,000	1	1
£110,001 - £120,000	1	1

No remuneration was paid to the trustees of The Thalidomide Trust Company Ltd (2021: £nil). Travel and subsistence expenses of £6,000 (2021: £2,500) were reimbursed to 4 (2021: 4) trustees of The Thalidomide Trust Company Ltd during the year.

The total remuneration and benefits received by the Trust's key management personnel was £294,000 (2021: £270,000) for 3 employees (2021: 3).

8 Tangible assets

Tangible assets comprise the following:

	Motor Vehicles £000s	Furniture & equipment £000s	Building £000s	Total £000s
Cost				
At 1 October 2021	52	12	465	529
Additions	26	-	-	26
Disposals	(24)	-	-	(24)
At 30 September 2022	54	12	465	531
Accumulated depreciation				
At 1 October 2021	23	1	175	199
Charged	13	2	10	25
Disposals	(17)	-	-	(17)
At 30 September 2022	19	3	185	207
Net book value				
At 30 September 2022	35	9	280	324
At 30 September 2021	29	11	290	330

All tangible fixed assets are unrestricted.

9 Investments

	2022 £000s	2021 £000s
Unlisted investments		
Global Unit Trusts (Equities)	127,794	137,236
Global Unit Trusts (Fixed Income)	25,698	30,631
UK Charity Funds	15,834	17,461
Cash held for investments (including accrued investment income)	1,265	806
Total per Balance Sheet	170,591	186,134

All investments are held as unrestricted funds.

9 Investments (continued)

The movement on investments in the year was as follows:

	2022 £000s	2021 £000s
Market value b/fwd 1 October 2021	186,134	151,765
Less: Disposal proceeds/ share exchanges	(67,610)	(45,463)
Add: Purchases at cost/share exchanges	65,401	40,954
Realised and unrealised gains/(losses)	(13,793)	39,506
Increase/(decrease) in cash held for investment (including accrued investment income)	459	(628)
Market value at 30 September 2022	170,591	186,134
Historical cost at 30 September 2022	157,336	142,189

The market value of investments has recovered this year, after dropping considerably the previous year due to the effect of the pandemic on the stock markets.

The trustees believe that the carrying value of the listed investments is supported by the underlying net assets.

10 Subsidiary

ValiDATE Trust was established on 7 August 2019 as a Private Limited Company by guarantee. The Thalidomide Trust has taken advantage of the exemption under section 24.13A of the Charities SORP, and not consolidated the results of ValiDATE Trust in the Group financial statements.

All costs associated with the establishment of the company were incurred by the Trust and recharged to the company.

At the 30 September 2022, ValiDATE Trust owed the parent company, The Thalidomide Trust, £35,000 (2021: £33,000).

The results of ValiDATE Trust for the period ended 30 September 2022 are shown below. Audited Accounts are filed with the Registrar of Companies.

	2022 £
Turnover and other income	25,560
Cost of sales and expenses	(20,879)
Profit for the year	4,681
Profit and loss reserves	(14,948)

11 Trust Fund including comparatives

	Unrestricted funds			
	Designated Beneficiary Memorandum Accounts £000s	General Fund £000s	Restricted Fund £000s	Total Trust Funds £000s
Balance as at 1 October 2021	3,253	171,499	(116)	174,636
Net incoming/(outgoing) resources as per Statement of Financial Activities	-	(17,508)	682	(16,826)
Adjustment for net increase in beneficiary memorandum accounts (note 12)	349	(349)	-	-
Balance as at 30 September 2022	3,602	153,642	566	157,810
	Note 12		Note 5	

	Unrestricted funds			
	Designated Beneficiary Memorandum Accounts £000s	General Fund £000s	Restricted Fund £000s	Total Trust Funds £000s
Fixed Assets				
Tangible	-	324	-	324
Investments	2,941	167,650	-	170,591
Current Assets				
Debtors and Prepayments	-	111	-	111
Advance of Grants	-	1,620	-	1,620
Cash at Bank and in Hand	661	1,231	6,205	8,097
Creditors: amounts falling due within one year				
Beneficiary nominee accounts	-	(17,007)	(5,639)	(22,646)
Creditors and accrued expenses	-	(287)	-	(287)
Balance as at 30 September 2022	3,602	153,642	566	157,810
	Note 12		Note 5	

Notes to the financial statements for the year ended 30 September 2022 (continued)

11 Trust Fund including comparatives (continued)

Comparatives	Unrestricted funds		Restricted Fund £000s	Total Trust Funds £000s
	Beneficiary Memorandum Accounts £000s	General Fund £000s		
Balance as at 1 October 2020	3,802	137,160	(173)	140,789
Net incoming/(outgoing) resources as per Statement of Financial Activities	-	33,790	57	33,847
Adjustment for net increase in beneficiary memorandum accounts	(549)	549	-	-
Balance as at 30 September 2021	3,253	171,499	(116)	174,636
	Note 12		Note 5	

Comparatives	Unrestricted funds		Restricted Fund £000s	Total Trust Funds £000s
	Beneficiary memorandum Accounts £000s	General Fund £000s		
Fixed Assets				
Tangible	-	330	-	330
Investments	2,732	183,402	-	186,134
Current Assets				
Debtors and Prepayments	-	100	-	100
Advance of Grants	-	1,963	-	1,963
Cash at Bank and in Hand	521	2,742	4,985	8,248
Creditors: amounts falling due within one year				
Beneficiary nominee accounts	-	(16,807)	(5,101)	(21,908)
Creditors and accrued expenses	-	(231)	-	(231)
Balance as at 30 September 2021	3,253	171,499	(116)	174,636
	Note 12		Note 5	

12 Beneficiary accounts

	Beneficiary memorandum accounts £000s	Beneficiary nominee accounts £000s	Beneficiary Health Grant accounts £000s	Total 2022 £000s	Total 2021 £000s
As at 1 October 2021					
Balance Sheet- Beneficiary Nominee Accounts		16,807	5,101	21,908	19,418
Balance Sheet- Beneficiary Memorandum Accounts	3,253				
Annual Grant Allocations	2,206	18,407		20,613	19,244
Health Grant Allocations			11,547	11,547	11,112
Payments from Beneficiary Accounts	(2,333)	(17,731)	(11,009)	(31,073)	(28,415)
Transfers between Nominee and Memorandum Accounts	476	(476)			
Adjustment for net decrease/ (increase) in Beneficiary Memorandum Accounts				(349)	549
As at 30 September 2022:					
Balance Sheet- Beneficiary Nominee Accounts		17,007	5,639	22,646	21,908
Balance Sheet- Beneficiary Memorandum Accounts	3,602				
	Note 11				

Beneficiary Memorandum Accounts are all designated funds and include: accounts for beneficiaries who lack capacity to manage their financial affairs (as detailed at note 5) and backdated grants allocated to new beneficiaries accepted by the Trust. On the death of a beneficiary, any funds held in Memorandum Accounts revert to the General fund to be used for the benefit of the wider community.

Beneficiary nominee accounts include the grant funds to which a beneficiary has absolute entitlement and which have not been requested by beneficiaries at the year-end (as detailed in note 5).

Beneficiary Health Grant accounts include the Health Grant funding made available, but not requested by beneficiaries (as detailed in note 5).

13 Taxation

The Trust is a registered charity, and as such is entitled to certain tax exemptions on income and profits from investments, and surpluses on any trading activities carried on in furtherance of the charity's primary objectives, if these profits and surpluses are applied solely for charitable purposes.

During the current and prior years, all distributions to beneficiaries were paid under the terms of Statutory Instrument 2004 No 1819, which allows distributions from the Trust to be paid free of income tax, and therefore no income tax liability arose.

14 Pension obligations**Defined contribution scheme**

Permanent staff are eligible to receive a pension provision equivalent to 10% of gross salary under a defined contribution scheme. During the year employer contributions to this scheme amounted to £75,000 (2021: £70,000).

At the end of the year other creditors and accruals included £10,700 (2021: £8,900) payable in respect of employer pension contributions.

15 Debtors

	Total funds 2022 £000s	Total funds 2021 £000s
Advances of Grants		
amounts falling due within one year	574	625
amounts falling due after one year	1,046	1,338
Other debtors	35	32
Prepayments and accrued income	76	68
Total	1,731	2,063

As set out in note 5, the Trustees will consider requests for Major Advances and Emergency Advances. The Advances consist of Major Advances and Emergency Advances balances as at 30 September 2022. Advances are recoverable from future Annual Grant allocations. Emergency Advances are recoverable within one year, Major Advances are recoverable up to a maximum of ten years.

16 Creditors

	Total funds 2022 £000s	Total funds 2021 £000s
Creditors: amounts falling due within one year		
Beneficiary nominee accounts (note 12)	22,646	21,908
Other creditors and accruals	287	231
Total	22,933	22,139

17 Net Debt Disclosure

	At 1 October 2021	Cash-flows	Other non- cash changes	At 30 September 2022
	£	£	£	£
Cash	8,248	(151)	-	8,097
Cash held for investment	806	459	-	1,265
Total	9,054	308	-	9,362

18 Related Party Transactions

Other than expenses paid to Trustees (see note 7), there were no related party transactions during the year.

During the period, the charity made payments for expenditure of its subsidiary, ValiDATE Trust of £2,000 (2021: £8,000).

At the year end, the Trust was owed £35,000 (2021: £33,000) from the ValiDATE Trust. This balance is presented within other debtors.

There is no parent undertaking. The ultimate controlling party is The Thalidomide Trust Company Ltd.

19 Comparatives for Statement of Financial Activities

Comparatives		Unrestricted Funds £000s	Restricted Funds £000s	Total Funds 2021 £000s
	Note			
Income from:				
Diageo donations	3	13,338	-	13,338
Health Department Grants	5	-	11,601	11,601
Investment income	2	2,165	1	2,166
Other income		90	-	90
Total		15,593	11,602	27,195
Expenditure on:				
Raising funds (solely investment management fees)	6	(444)	(3)	(447)
Charitable activities	6	(20,865)	(11,542)	(32,407)
Total		(21,309)	(11,545)	(32,854)
Net gains/(losses) on investments	9	39,506	-	39,506
Net income (expenditure)		33,790	57	33,847
Reconciliation of Funds				
Fund balances brought forward At 1 October 2020	11	140,962	(173)	140,789
Fund balances carried forward at 30 September 2021	11	174,752	(116)	174,636

THE THALIDOMIDE TRUST

England & Wales - Charity number 266220

Accounts

The Thalidomide Trust

Annual Report and Financial Statements
for the year ended 30 September 2021

Registered Charity Number 266220

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Reference and administrative details

Registered Name	The Thalidomide Trust
Charity number	266220
Registered address	1 Eaton Court Road Eaton Socon St Neots Cambridgeshire PE19 8ER
Corporate Trustee	The Thalidomide Trust Company (incorporated on 19 January 2018 with Company Number 11160424, registered address as above)

Directors of the Corporate Trustee Company

The Directors of The Thalidomide Trust Company during the year and up to the date of approval were:

Sir Robert Nelson QC (Chair of Trustees to 31 December 2020)

Mark Spofforth OBE BSc FCA CTA FRSA (Chair of Trustees from 1 January 2021)

Professor Tim Briggs CBE MD(Res), MCh(Ort), FRCS

Marlene Winfield OBE (Vice-Chair of Trustees) – retired 31 August 2021

Kevin Wesbroom MA MA FIA

Mark Benstead MA MBA

David Body MA Solicitor of Senior Courts of England & Wales

Professor Adrian Charles Newland CBE

Professor William Andrew Owens MD FRCS(CTh)

Professor Rosemary Varley

Ruthe Isden – appointed 1 September 2021

Senior Management Team	Deborah Jack - Executive Director Katy Sagoe - Director of Health & Wellbeing Suzanne Lluch - Finance Director
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Medical Advisers	Dr Dee Morrison MB ChB Dr Susan Brennan MBChB MRCGP
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Chair of NAC

Geoff Adams-Spink – to 9 October 2020

Rowland Bareham – from 10 October 2020

Investment Managers

BlackRock
12 Throgmorton Avenue
London
EC2N 2DL

TwentyFour Asset Management
8th Floor
The Monument Building
11 Monument Street
London EC2R 8AF

Schroders Investment Management Limited
1 London Wall Place
London Wall
London
EC2Y 5AU

Legal & General Investment Management
One Coleman Street
London
EC2R 5AA

Investment Consultants

Hymans Robertson
45 Church Street
Birmingham
B3 2RT

Solicitors

Withers
20 Old Bailey
London
EC4M 7AN

Hewitsons
Shakespeare House
42 Newmarket Road
Cambridge
CB5 8EP

Actuaries

Mercer
1 Tower Place West
London
EC3R 5BU

Bankers

Lloyds Bank
39 Threadneedle Street
London
EC2R 8AU

Independent auditors

Saffery Champness LLP
Westpoint
Peterborough Business Park
Lynchwood
Peterborough
PE2 6FZ

Annual Report

Objectives and activities

The Thalidomide Trust (“the Trust”) was established to provide ‘relief and assistance’ to individuals with disabilities caused by their mothers taking, during pregnancy, a preparation distributed by The Distillers Company (Biochemicals) Limited in the United Kingdom containing the drug known as thalidomide in the late 1950s and early 1960s.

Our aims

All our beneficiaries are now in their late 50s and early 60s and most are feeling the impact of using their bodies in ways for which they were never designed. In addition, as they get older they are experiencing a wide range of age-related health problems which are exacerbated by their original thalidomide damage. This seriously impacts on their quality of life and their ability to remain fully independent. A small number have experienced a cognitive decline alongside the deteriorating physical health and this has resulted in very complex care needs.

The Trust meets the increasing complex needs of the beneficiary community through the provision of financial support – in the form of annual grant payments – and a range of information, advice and advocacy services. To underpin this, we gather evidence on the needs and experience of our beneficiaries and undertake more detailed research on topics that are of greatest relevance to them.

The Trust has a Vision and five Strategic Goals which were jointly developed by the trustees, staff and National Advisory Council (NAC) of beneficiary representatives:

Our Vision is that all beneficiaries of the Trust have access to the resources and support they need to optimise their quality of life throughout their lifetime.

Our five strategic goals are.....

- GOAL 1:** To ensure a beneficiary-centred approach in all Trust activities - with an emphasis on equity, empowerment and support.
- GOAL 2:** To ensure sustainability and security of income for the Trust and manage financial risk in order to effectively meet the needs of existing and new beneficiaries for the whole of their lives.
- GOAL 3:** To apply the Trust’s resources effectively and equitably.
- GOAL 4:** To ensure that all beneficiaries have access to the best possible information, advice, services and support – both within and outside the Trust – as they age.
- GOAL 5:** To inform and educate those decision-makers and service providers who have an impact on the quality of life of beneficiaries.

Public Benefit

Although the Trust is very much focussed on the needs of a small, discrete community of beneficiaries, we also take steps to deliver a broader public benefit by sharing our research and learning with other thalidomide organisations around the world and, where relevant, with the broader disability community.

The Trust supports an agreed programme of campaigning activities undertaken by the beneficiary-led Campaigns Team. This is designed to achieve clear agreed outcomes, one of which is increasing public understanding of the thalidomide scandal - to help prevent similar failures occurring - and to highlight the ongoing needs and challenges affecting the Trust's beneficiaries.

The Trust is increasingly aware of the benefit of sharing lessons learned from almost fifty years of supporting this unique community with other groups of individuals living with disabilities and the organisations that support them and is currently exploring ways of doing this.

Structure, Governance and Management

Structure

The Thalidomide Trust was set up in 1973 - originally as the Thalidomide Children's Trust - and is a charitable discretionary Trust registered with the Charity Commission for England and Wales.

With the consent of the Charity Commission, on 29 January 2018 a new company limited by guarantee, The Thalidomide Trust Company (incorporated on 19 January 2018, Company Number 11160424), was appointed as sole Corporate Trustee of the Trust, replacing the individual trustees. The Corporate Trustee will be referred to in this document as the Trustee.

The trustees at the date of incorporation became the Directors of the Company. However, although legally Directors, in recognition of the fact that they function as trustees and operate within the legal frameworks and guidance of the Charity Commission, they continue to be referred to as trustees. To reflect this, they are referred to as trustees (as opposed to the Trustee above) throughout this Annual Report.

During 2019/20, we set up a new company limited by guarantee as a subsidiary of the Thalidomide Trust, with the consent of the Charity Commission. The validATE Trust (registered in England and Wales, with company number 12144047) operates on a not-for-profit basis. It was established specifically to oversee the maintenance and development of an online tool to be used by qualified clinicians to screen individuals using detailed medical data in order to assess the likelihood of Thalidomide Embryopathy (TE). This Diagnostic Algorithm for Thalidomide Embryopathy was one of the key outputs of a meeting of international thalidomide experts organised by the World Health Organisation (WHO) and is designed to be used worldwide to ensure consistent diagnosis of TE, based on the latest international evidence.

Trustees (formally Directors of the Trustee Company)

The Trust is governed by a small, skilled Board who bring a wealth of experience and expertise to the charity including medical, legal, research, governance, financial management and investment.

Trustees are appointed through a structured recruitment process which focusses on the skills required to meet the current and future needs of beneficiaries. The recruitment process is overseen by the Trust's Chair and there is direct beneficiary involvement in all trustee appointments. Our most recent trustee appointment was a policy expert specialising in health, care and ageing.

The Trust has a well-defined and comprehensive programme of induction for new trustees and all new trustees are offered a mentor from within the existing trustee Board.

The trustees are legally responsible for the overall management and control of the Trust and meet as a full Board at least three times a year. One of these three meetings is an Awayday which enables the trustees and the Trust's Senior Management Team to spend dedicated time focussing on long term strategic issues.

The Trust has two key Standing Committees - the Health & Wellbeing Committee and the Finance Committee - which met two and four times respectively during this year. Both Committees are attended by representatives from the Trust's National Advisory Council (NAC). The Health & Wellbeing Committee is jointly-chaired by a trustee and a beneficiary chosen by the NAC.

There are two additional Committees which met on an ad hoc basis during 2020/21. They are:

- Claims Committee, which considers all evidence and makes recommendations to the Board regarding whether applicants should be accepted as new beneficiaries of the Trust.
- Research Committee, which oversees all research involving the Trust and its beneficiaries and commissions and shapes new research projects.

Staff Team

The day to day running of the Trust is delegated to the Executive Director, supported by a small, dedicated and skilled staff team.

The majority of staff are focussed on supporting beneficiaries in relation to their health and wellbeing in order to maximise their independence and quality of life.

Remuneration Policy

The trustees are responsible for the Trust's remuneration policy as well as agreeing annual pay increases for the staff team. Trustees take account of market conditions and the pay practice of other comparable charities and employers in the geographic area.

National Advisory Council (NAC)

The Trust Deed makes provision for the appointment of a beneficiary National Advisory Council to advise trustees on a range of issues. The NAC is currently comprised of 12 beneficiaries who are elected by the beneficiary community to represent their views and needs.

Elections are held each February when three members are currently elected for a four year term of office. The NAC elects a chair from among the elected members. The trustees have responsibility for making regulations relating to the election and removal of members of the NAC.

There were two meetings of the NAC during the year, which were attended by trustees and staff representatives. Agendas for these meetings are circulated to all beneficiaries in advance to enable them to feed in their views. In addition, summary notes and minutes of the meetings are shared with the beneficiary community after the meeting and there is an opportunity for beneficiaries to participate in an interactive discussion, via Zoom, with selected NAC members.

Beneficiary representatives from the NAC attend meetings of the Board, Finance Committee, Health & Wellbeing Committee and Research Committee to represent the views of the beneficiary community to inform the Trust's decision-making.

During the year, the NAC published regular newsletters to keep the beneficiary community informed of its, and the Trust's, activities. They also individually produced an 'annual report' – in both written and video format - highlighting their activities and achievements over the previous 12 months and, collectively, a short video report for the beneficiaries.

NAC representatives attended all Trust events, which provided opportunities for them to meet with the beneficiary community to share information and seek feedback.

Volunteers

A number of beneficiaries generously volunteer their time and expertise to support the Trust and, through it, the broader beneficiary community.

In the last 12 months over 50 beneficiaries volunteered their time in a wide range of roles including: providing (practical and emotional) peer support; hosting virtual discussions/events for beneficiaries; membership of the NAC; sitting as beneficiary representatives on Trust Committees; attending meetings with the four UK Health and Social Care Departments and contributing to various Trust projects.

Beneficiaries

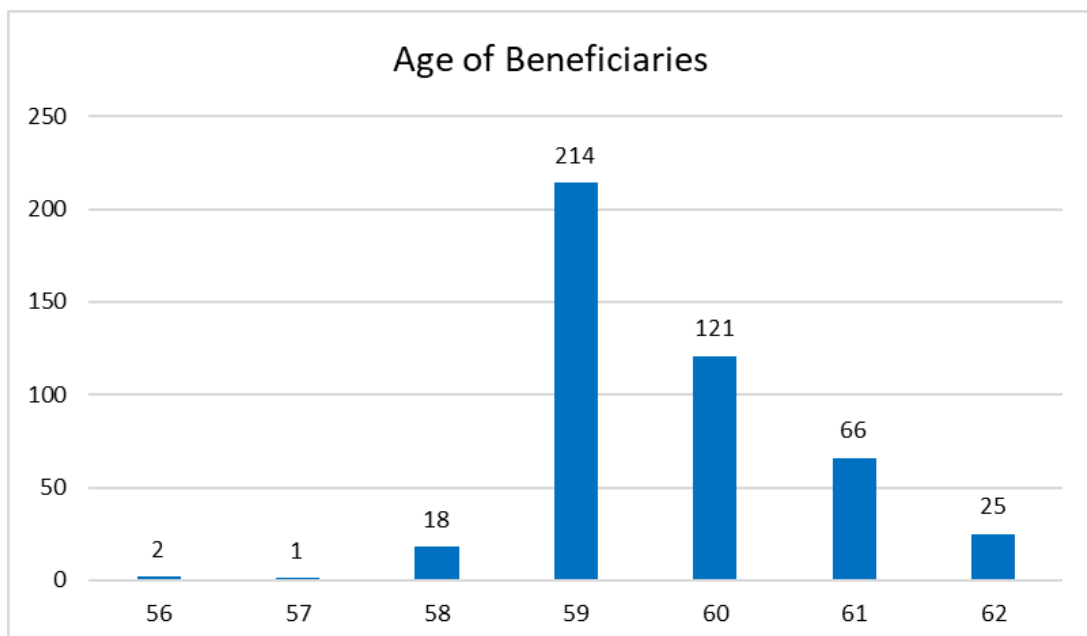
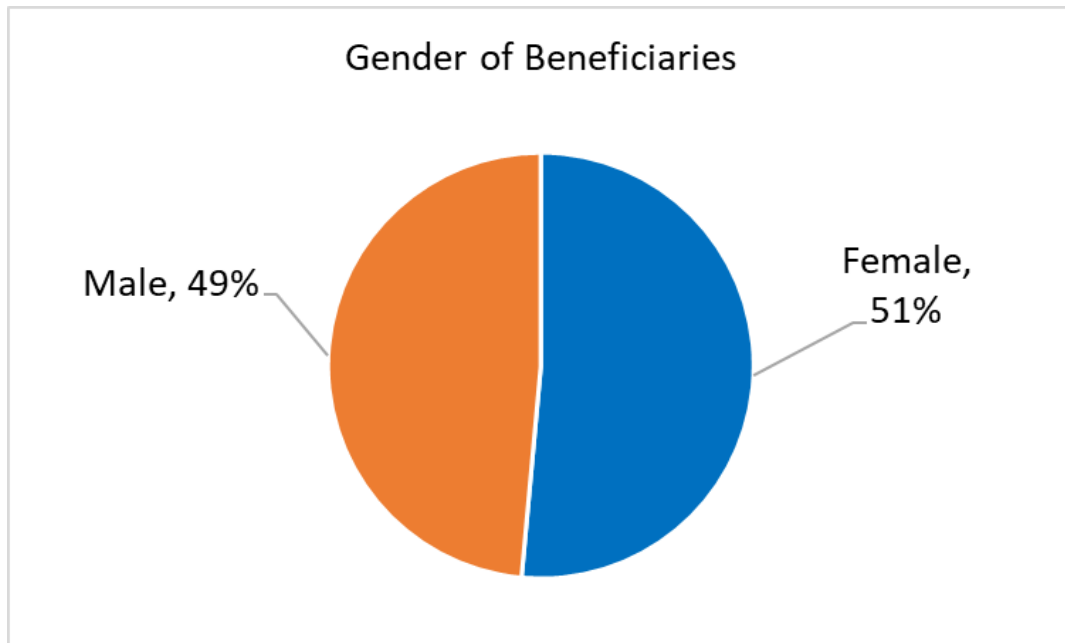
The Trust has responsibility for assessing new applications to become beneficiaries of the Trust and has established a robust procedure for assessing new applications, drawing on international evidence and utilising the diagnostic algorithm, validATE, which was one of the key outputs of the WHO conference on Thalidomide Embryopathy held in early 2014.

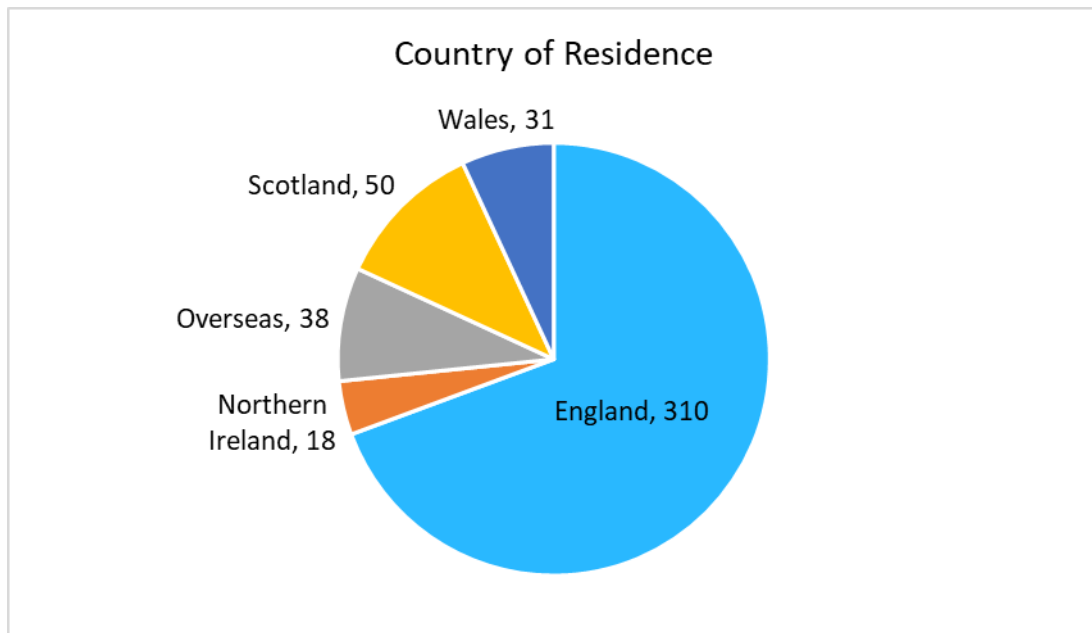
During the year, the Trust received 63 completed applications from individuals who thought they may be entitled to become beneficiaries.

There were significant delays in completing the detailed assessment process – which, in some cases, involves a physical examination conducted at St George’s hospital – so there were no new beneficiaries accepted in the 12 month period.

It is with regret that the trustees report the deaths of seven beneficiaries during the year. At 30 September 2021 there were 447 beneficiaries (2020: 454).

The following charts provide a breakdown of beneficiaries by gender, age and country of residence as at 30 September 2021.





Risk Management

A key role of trustees is to identify and manage risk and they discharge this duty by means of a Risk Register. The full Risk Register is reviewed by trustees annually. The most significant risks are reviewed by the Finance Committee on a quarterly basis. This year, the trustees have satisfied themselves that adequate systems and procedures are in place to manage all of the identified risks.

The principal risks and uncertainties identified by trustees in their 2021 risk review continued to be the security of future funding and of the Trust's IT systems (including the risk of data security breaches or potential fraud, theft of funds and breach of beneficiary confidentiality). Plans to mitigate these significant risks as far as possible are regularly reviewed and updated by the trustees.

We have continued to gather robust evidence on the evolving and increasing needs of our beneficiaries and to share this with our funders, together with information on how their funding is improving beneficiaries' quality of life. Our most recent Covenant with Diageo (our primary funder and the successor to the Distillers Company Ltd who distributed thalidomide in the UK) includes new measures to provide greater security of future funding for our beneficiaries. In March 2021, the Chancellor of the Exchequer, announced the government's commitment to providing funding for beneficiaries living in England for the rest of their lives. Both these measures provide much-needed security for beneficiaries at a time when their needs are increasing.

Following our move to cloud-based data storage and switching to a fully managed service provider in 2020, in the last 12 months we have further strengthened our IT security by improving our data back-up procedures, undertaking external penetration testing and a phishing simulation campaign, and provided further cyber security awareness training for staff.

The trustees treat safeguarding of our beneficiaries as an important priority and have a robust safeguarding policy in place. Sadly, during the 12-month reporting period, in three cases the Trust identified safeguarding concerns relating to family members or carers and reported them to external bodies (Local Authority Safeguarding leads and/or the police).

Achievements and Performance

This has been another challenging year for the Trust as the continuing COVID-19 pandemic created additional needs within the beneficiary community, put incredible pressure on the NHS which so many of them rely on, and required the majority of staff to work at home for most of the year. We also needed to modify a number of the ways we traditionally deliver support to the beneficiary community. For example, we had to undertake a proportion of Holistic Needs Assessments – which normally take place face-to-face in a beneficiary's home environment - by Zoom and, rather than hold physical events, we held these on virtual platforms.

Over the year we developed our programme of beneficiary-led MeetUp events which provided a lifeline to many beneficiaries who were experiencing isolation and loneliness. These covered a range of formats and topics from virtual coffee mornings to webinars on health-related topics (including men's health, health eating, smoking cessation) and groups of beneficiaries with a shared interest (as diverse as crafts, football, reading and Indian cooking).

At the start of the year we identified a number of ambitious goals for 2020/21. These are set out below together with an overview of the progress made over the last 12 months:

We said we would...	We ...
Pilot a new initiative to assess cardiovascular risk when a traditional blood pressure measurement is not possible.	... held a series of discussions with BUPA – who we had identified as our preferred partner – to discuss piloting a tailored cardiovascular risk screening pathway for our beneficiaries but, unfortunately, they did not have the staff capacity or skills to deliver this to our specification – so we are in the process of exploring alternative providers.
Hold a virtual event for members of our Clinical Network to promote sharing knowledge and experience of treating our beneficiaries.	.. scheduled and planned an event with an expert speaker from the Royal National Orthopaedic Hospital but, due to circumstances beyond our control, this had to be cancelled at short notice. We are looking to re-schedule this in early 2022.
Develop new resources for beneficiaries on managing chronic pain.	 created a range of written and video resources on persistent pain which are on our website and have received positive feedback from beneficiaries.
Launch a new tailored Emergency-Card so that health professionals treating our beneficiaries have access to key information about their thalidomide damage and other health issues.	... created a bespoke Emergency Card, working in partnership with MyLiferaft, and launched this in December 2020.

• Build on our current work supporting beneficiaries with initiatives to lift their mood and improve their physical fitness.	.. have continued to develop our LiftUp and TalkTogether services – which are primarily delivered by beneficiary volunteers. undertook a programme of wellbeing calls to offer emotional support during the pandemic. ... now provide a wealth of information on mental health on our website and have developed links with a number of professionals with particular expertise in trauma. ..have a specialist counsellor who is available to triage beneficiaries and help them identify an appropriate counsellor to meet their individual needs. ...have concluded our project with Loughborough University to explore the barriers to exercise within the beneficiary community and use the findings to develop a pilot intervention to encourage increased activity. The successful pilot is being turned into a new peer support service led by beneficiary volunteer ‘Activity Champions’
• Take forward our plans to develop a tailored resource for Occupational Therapists.	.. made progress on this project but have not yet been able to complete the video case studies – which are an integral part of the resources – due to the restrictions of COVID-19.
• Undertake a review of our new Exceptional Needs Fund and making recommendations for change, if required.	.. decided to put the review on hold as the number of applications to the Exceptional Needs Fund were significantly lower than expected during the reporting period.
• Introduce online voting for our NAC elections to encourage greater participation amongst the beneficiary community.	... introduced an online voting system, alongside the traditional printed ballot papers, for the NAC election in early 2021. This was well-received by a number of beneficiaries

Plans for the Future

In the next 12 months, the trustees, staff and members of the NAC will continue to work together to implement their jointly-owned Strategic Plan. Subject to the uncertainties created by the continuing Covid-19 pandemic, our plans include:

- Conducting a comprehensive Beneficiary Feedback Survey
- Holding an event for new beneficiaries to encourage them to feel more part of the Trust
- Creating tailored resource for social care assessors and frontline care staff– to increase their understanding of thalidomide damage and the impact it has on daily life
- Undertaking a review of our Emergency-card, including feedback from users
- Producing a report of the recently-concluded Upper Limb Research Study
- Delivering an online event to provide information, advice and guidance to professionals supporting beneficiaries who lack capacity.
- Recruiting additional members to our Clinical Network with expertise rehabilitation, pain management and mental health.

Financial Review

During the year the Trust allocated grants totalling £30.4M (2020: £31.6M) to its beneficiaries. The Trust received donations from Diageo plc totalling £13.3M (2020: £13.2M – this figure excludes backdated payments for new beneficiaries).

Health Grant funding from the four Health and Social Care Departments of the United Kingdom totalled £11.6M (2020: £11.2M). As Health Grant funding is provided for specific, agreed health and wellbeing purposes, these are accounted for by the Trust as funds restricted for these purposes.

The Trust is committed to managing its resources effectively and achieving value for money. It operates a robust budget management system which involves regular review of activity and expenditure by budget holders, oversight by the Management Team and regular reporting of variances to the Trust's Finance Committee. The Trust does not actively fundraise and 100% of its resources are utilised for charitable purposes, including charity governance. During 2020/21, 92% of outgoing resources were in the form of Grants to our beneficiaries. Of the remaining 8% of expenditure, 70% (excluding investment management fees) was spent on providing health and wellbeing support and financial guidance directly to our beneficiaries by our staff and volunteers. The balance of resources was utilised to administer beneficiary Grants, assess new claims, ensure effective governance of the Trust, and deliver agreed campaigning activities.

Investment Objectives

The principal objective of the investment policy is to generate sufficient income and capital return to enable the trustees to pay Annual Grants for the entire lives of the beneficiaries.

The environmental, social and governance (ESG) nature of Trust investments has been considered at length by the trustees. The trustees believe that ESG-related risks, including climate change risks, are financially material and an important component of investment risk. The Trustees believe that organisations that soundly manage ESG-related risks are more likely to be financially sustainable over time, and therefore deliver better long-term risk-adjusted returns. In October 2020, trustees moved £30m of funds into a new ESG fund with Legal & General Investment Management (LGIM).

As all of the Trust investments are held within pooled funds, the decisions regarding the selection of investments is entrusted to the investment managers, who each act within agreed guidelines. Trustees regularly ask investment managers to explain how ESG factors are incorporated into their decisions regarding the selection of investments.

In line with the 2018 Covenant with Diageo, the trustees adopted an investment policy which will reduce the investment risk of the portfolio over the lifetime of the Trust.

In order to achieve this, from 2017 to 2022 the trustees will continue to try to achieve higher returns with a given amount of risk, managed through diversification and active management of the investment assets. From 2022 to 2037 trustees expect to smoothly reduce the investment risk of the portfolio.

The current benchmark against which performance between 2017 and 2022 is represented by a portfolio comprising of 75% global equities and 25% bonds.

Investment Strategy and Performance

The investment strategy is currently implemented through a combination of investments and managers as set out in the table below, together with the ranges within which the policy is managed, in line with the Statement of Investment Principles dated December 2020.

Portfolio	Manager	Central Allocation (% of Assets)	Target Ranges (% of Assets)
Active Global Equities	Schroders	30	20-40
Passive Global Equities	BlackRock and LGIM	50	40-60
Bond Portfolios	BlackRock and 24AM	20	10-30
Cash	Lloyds and RLAM	0	0-20

Cash deposits are held with a variety of banks and investment managers.

The total annual return on the Trust's investments for the year was 29.4% (2020: -5.7%) which is higher than the benchmark of 16.6%.

Over the last three years the average rate of return has been 8.5% pa, which is slightly lower than the benchmark of 9.2%.

Significant Investments

At the year end, the following investments represented 5% or more of the total market value of investments:

	£000s	%
Schroders Global Recovery Fund	47,219	25
Legal and General Future World ESG Fund	36,905	20
Black Rock North America	34,572	19
Schroders UK Equities	15,444	8
Vontobel –24AM Strategic Income Fund	15,185	8
BlackRock Fixed Income Global Opportunities Fund	14,816	8

Derivative Instruments

The trustees have authorised Schroders to use financial contracts, known as derivatives, to help manage investment portfolio risk. At the year end the open derivatives position was a net liability of £0 (note 9) (2020: net liability of £35,000).

Diageo Covenant

A Deed of Covenant is in place, signed by the trustees and Diageo plc (successor to The Distillers Company), which sets out Diageo's commitment to long-term support for Thalidomide Trust beneficiaries and to underwrite the investment policy of the Trust. The Covenant enables the Thalidomide Trust both to maintain the programme of Annual Grants

to its beneficiaries and deliver ongoing support in response to their evolving and growing health and wellbeing needs.

The Deed of Covenant is reviewed by the trustees, the NAC and Diageo every six years. In January 2018, an updated Deed of Covenant was agreed which reflects an increased level of support from Diageo.

Government Health Grants

In addition to the assets held by the Trust and the income from Diageo, the UK government supports the Trust by way of Health Grant funding agreements in place with the four UK Health and Social Care Departments since 2009. This money has helped beneficiaries to respond to their growing needs as they age – in order to maximise their independence and quality of life, minimise further deterioration and improve their overall health and wellbeing. The existing 10 year Health Grant agreements come to an end in 2023 (with the last grant payments made to beneficiaries in June 2022). In March 2021, the Chancellor, Rishi Sunak, announced a commitment to lifetime funding of the Health Grant to beneficiaries living in England. Discussions are underway with the devolved administrations over a similar renewal commitment for beneficiaries living in Wales, Scotland and Northern Ireland.

Grant Making and Reserves Policy

Beneficiaries receive an Annual Grant, based on their level of disability, from funds that come from Diageo each year in line with the Covenant and the Trust's reserves, including the interest and investment growth accrued.

The trustees' distribution policy continues to provide individual Annual Grants to beneficiaries for the whole of their lives. The trustees have to set a policy which will ensure reserves are not depleted whilst beneficiaries are in need of funding, whilst at the same time ensuring all assets are utilised by the time of the death of the last beneficiary. The total unrestricted funds at 30 September 2021 stood at £175M (2020: £141M) whereas the Restricted Fund had a deficit of £0.1M at the year-end (2020: £0.2M) due to the timing of Health Grant receipts and payments. This deficit is expected to be eliminated by the end of the current ten year Health Grant period.

Statement of the Corporate Trustee's Responsibilities

The Trustee is responsible for preparing the Trustee's Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England and Wales requires the Trustee to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and their application for that period.

In preparing these financial statements, the Trustee is required to:

- select suitable accounting policies and then apply them consistently
- observe the methods and principles in the Charities SORP (Statement of Recommended Practice)
- make judgments and estimates that are reasonable and prudent

- state whether applicable accounting standards, comprising FRS 102, have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis¹ unless it is inappropriate to presume that the charity will continue in business.

The Trustee is responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable it to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. The Trustee is also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustee is responsible for the maintenance and integrity of the charity and financial information included on the charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Signed on behalf of the Corporate Trustee:

Mark Spofforth
Chair of the Board of the Thalidomide Trust Company
27 January 2022

¹ The going concern basis means that the charity has the resources to continue in operations for a minimum of 12 months from the date of signing these financial statements

Independent auditors' report to the trustee of The Thalidomide Trust

Report on the audit of the financial statements

Opinion

We have audited the financial statements of The Thalidomide Trust for the year ended 30 September 2021 which comprise the balance sheet as at 30 September 2021; the statement of financial activities for the year then ended; cashflow statement for the year and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102, the Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 30 September 2021 and of its incoming resources and application of resources for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information; we are required to report that fact.

We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 require us to report to you if, in our opinion:

- the information given in the Trustees' Annual Report is inconsistent in any material respect with the financial statements; or
- the charity has not kept sufficient accounting records; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the Trustees' Responsibilities Statement set out on page 16, the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Auditors' responsibilities for the audit of the financial statements

We have been appointed as auditors under the Charities Act 2011 and report in accordance with regulations made under that Act.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditors' report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The specific procedures for this engagement and the extent to which these are capable of detecting irregularities, including fraud are detailed below.

Identifying and assessing risks related to irregularities:

We assessed the susceptibility of the charity's financial statements to material misstatement and how fraud might occur, including through discussions with the trustees, discussions within our audit team planning meeting, updating our record of internal controls and ensuring these controls operated as intended. We evaluated possible incentives and opportunities for fraudulent manipulation of the financial statements. We identified laws and regulations that are of significance in the context of the charity by discussions with trustees and updating our understanding of the sector in which the charity operates.

Laws and regulations of direct significance in the context of the charity include the Charities Act 2011, the Charities (Accounts and Reports) Regulations 2008 and guidance issued by the Charity Commission for England and Wales.

Audit response to risks identified:

We considered the extent of compliance with these laws and regulations as part of our audit procedures on the related financial statement items including a review of financial statement disclosures. We reviewed the charity's records of breaches of laws and regulations, minutes of meetings and correspondence with relevant authorities to identify potential material misstatements arising. We discussed the charity's policies and procedures for compliance with laws and regulations with members of management responsible for compliance.

During the planning meeting with the audit team, the engagement partner drew attention to the key areas which might involve non-compliance with laws and regulations or fraud. We enquired of management whether they were aware of any instances of non-compliance with laws and regulations or knowledge of any actual, suspected or alleged fraud. We addressed the risk of fraud through management override of controls by testing the appropriateness of journal entries and identifying any significant transactions that were unusual or outside the normal course of business. We assessed whether judgements made in making accounting estimates gave rise to a possible indication of management bias. At the completion stage of the audit, the engagement partner's review included ensuring that the team had approached their work with appropriate professional scepticism and thus the capacity to identify non-compliance with laws and regulations and fraud.

There are inherent limitations in the audit procedures described above and the further removed non-compliance with laws and regulations is from the events and transactions reflected in the financial statements, the less likely we would become aware of it. Also, the risk of not detecting a material misstatement due to fraud is higher than the risk of not detecting one resulting from error, as fraud may involve deliberate concealment by, for example, forgery or intentional misrepresentations, or through collusion.

A further description of our responsibilities is available on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the trustees as a body, for our audit work, for this report, or for the opinions we have formed.

.....

Saffery Champness LLP
Chartered Accountants and Statutory Auditors
Westpoint, Peterborough Business Park, Lynchwood, Peterborough, PE2 6FZ

Date:

Saffery Champness LLP is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

Statement of financial activities for the year ended 30 September 2021

	Note	Unrestricted funds £000s	Restricted funds £000s	Total funds 2021 £000s	Total funds 2020 £000s
Income from:					
Diageo donations	3	13,338	-	13,338	14,605
Health Department grants	5	-	11,601	11,601	11,153
Investment income	2	2,165	1	2,166	2,584
Other income		90	-	90	122
Total		15,593	11,602	27,195	28,464
Expenditure on:					
Raising funds (solely investment management fees)	6	(444)	(3)	(447)	(444)
Charitable activities	6	(20,865)	(11,542)	(32,407)	(31,871)
Total		(21,309)	(11,545)	(32,854)	(32,315)
Net gains/(losses) on investments	9	39,506	-	39,506	(13,217)
Net income (expenditure)		33,790	57	33,847	(17,068)
Reconciliation of funds					
Fund balances brought forward	11	140,962	(173)	140,789	157,857
At 1 October 2020/2019					
Fund balances carried forward					
at 30 September 2021/2020	11	174,752	(116)	174,636	140,789

All activities are continuing. All gains and losses recognised in the year are included in the Statement of Financial Activities.

Balance Sheet as at 30 September 2021

		Total funds 30/09/2021 £000s	Total funds 30/09/2020 £000s
	Note		
Fixed assets			
Tangible assets	8	330	342
Investments	9	186,134	151,765
		186,464	152,107
Current assets			
Debtors and prepayments	15	100	103
Advance of grants	15		
amounts falling due within one year		625	548
amounts falling due after one year		1,338	1,825
Cash at bank and in hand		8,248	6,029
		10,311	8,505
Creditors: amounts falling due within one year			
Beneficiary nominee accounts	12	(21,908)	(19,418)
Creditors and accruals	16	(231)	(405)
		(22,139)	(19,823)
Net current assets		(11,828)	(11,318)
Total assets less current liabilities		174,636	140,789
Net assets		174,636	140,789
Trust funds			
General fund	11	171,499	137,160
Beneficiary memorandum accounts	11,12	3,253	3,802
		174,752	140,962
Restricted fund	11	(116)	(173)
		174,636	140,789

The financial statements on pages 22 to 42 were approved by the Board on 27 January 2022 and signed on behalf of the Corporate Trustee by:

Mark Spofforth
Director

Mr K Wesbroom MA MA FIA
Director

Cash flow statement for the year ended 30 September 2021

		Total funds 2021 £000s	Total funds 2020 £000s
	Note		
Cash flows from operating activities:			
<i>Net cash provided by (used in) operating activities</i>		<u>(5,073)</u>	<u>(4,754)</u>
Cash flows from investing activities			
Dividends, interest and rents from investments		2,166	2,584
Purchase of tangible fixed assets	8	(12)	(51)
Proceeds from sale of tangible fixed assets		-	15
Purchase of investments	9	(40,954)	(7,316)
Proceeds from sale of investments	9	45,463	9,370
<i>Net cash provided by (used in) investing activities</i>		<u>6,663</u>	<u>4,602</u>
Change in cash and cash equivalents in the reporting period		1,590	(152)
Cash and cash equivalents as 1 October 2020		7,464	7,616
Cash and cash equivalents as at 30 September 2021		<u>9,054</u>	<u>7,464</u>
Cash held for investment	9	806	1,435
Cash at bank and in hand		8,248	6,029
Cash as at 30 September 2021		<u>9,054</u>	<u>7,464</u>
Reconciliation of income/(expenditure) to net cash (outflow) from operating activities			
<i>Net income/(expenditure) for the reporting period as per the statement of financial activities)</i>		33,847	(17,068)
Adjustments for:			
Depreciation & profit on disposals		24	21
(Gains)/losses on investments		(39,506)	13,217
Dividends, interest and rents from investments		(2,166)	(2,584)
Increase/(decrease) in creditors due within one year		2,316	1,181
(Increase)/decrease in debtors		412	479
<i>Net cash provided by (used in) operating activities</i>		<u>(5,073)</u>	<u>(4,754)</u>

Notes to the financial statements for the year ended 30 September 2021

1. Accounting policies

Basis of preparation

The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 and the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2011 and UK Generally Accepted Practice as it applies from 1 January 2015.

The financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following Accounting and Reporting by Charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

The Trust, which is an unincorporated discretionary charitable trust, constitutes a public benefit entity as defined by FRS 102. The sole trustee is the Thalidomide Trust Company, which is an incorporated trustee company. The financial statements have been prepared on a going concern basis (that is to say, that the charity has the resources to continue in operations for a minimum of 12 months from the date of signing these financial statements) and accounting policies have been applied consistently.

The undertaking by Diageo plc to make annual donation payments until 2037 and the Health Grant funding agreements that are in place until 2022, support the conclusion that the charity is a going concern.

The financial statements are prepared in sterling, which is the functional currency of the Trust, and rounded to the nearest £000. The date for authorisation of the issue of the financial statements was 27 January 2022.

The Thalidomide Trust has taken advantage of the exemption under section 24.13A of the Charities SORP not to prepare consolidated accounts. The financial statements present information about the Trust as an individual entity and not about its group.

Fund accounting

Unrestricted Funds

Unrestricted funds are expendable at the discretion of the trustees in the furtherance of the objects of the Thalidomide Trust. The Trust's level of reserves is maintained in order to meet the anticipated future grant allocations.

The General Fund and Beneficiary Memorandum Accounts are derived from funds provided by Diageo plc and its predecessors, and investment returns.

Notes to the financial statements for the year ended 30 September 2021 (continued)

1 Accounting policies (continued)

Restricted Funds

Restricted income funds are funds whose use is restricted to specific purposes according to the terms on which the funds were received. Where income is received for purposes specified by the donor that income is shown as restricted in the Statement of Financial Activities. Expenditure for the specified purposes is shown as restricted expenditure. Any unexpended balance at the balance sheet date is carried forward as a restricted income fund.

Restricted Funds are derived from the Health and Social Care Departments in England, Scotland, Wales and Northern Ireland as detailed in note 5.

Tangible fixed assets

As an unincorporated association, the Trust was not able to hold property in its own name and so in prior years the property was held in the names of the individual trustees. In January 2018, following the establishment of the sole corporate trustee, the Thalidomide Trust Company, title for the property transferred to the Thalidomide Trust Company, which is an incorporated trustee company. Beneficial ownership, and in substance control, remains with the Trust and the building is therefore disclosed in the financial statements of the Trust.

The cost of tangible fixed assets is their purchase cost, together with any incidental costs of acquisition. Depreciation is calculated so as to write off the cost of tangible fixed assets on a straight-line basis over the useful economic lives of the assets concerned.

The principal depreciation rates used are as follows:

Motor vehicles	-	25% per annum
Furniture and equipment	-	20% per annum
Buildings	-	2% per annum

The Trust has a capitalisation threshold of £2,500.

Tangible fixed assets are written down to their realisable value if it is considered there has been a permanent diminution in their value.

Investments

Unquoted unit trust investments are stated at the market value as established by the administrators of the unit trust. Market value is based upon the buying and selling price of the underlying securities in the relevant market with allowances made for cash, accrued income and costs within the unit trust fund.

Derivatives are initially recognised at transaction value and subsequently measured at their settlement value.

Notes to the financial statements for the year ended 30 September 2021 (continued)

1 Accounting policies (continued)

Income from investments

Income from investments is recognised when its receipt is probable and the amount receivable can be measured reliably. Any realised and unrealised gains and losses on revaluation or disposals are combined in the statement of financial activities.

Other incoming resources

Other income consists of fee income charged to beneficiaries, which is recognised upon the issuance of advances on future grants to beneficiaries. These advances are intended to assist with major property, mobility and health related purchases. The fee level is based on the cost to the Trust of making the advances, which includes a contribution towards the loss of income generated by the Trust's cash and investments as a result of withdrawing the cash to be advanced to the beneficiary.

Income from rent

Income from rent is recognised on a straight line basis over the period in which the service is provided.

Diageo donation

The Diageo donation is paid under the terms of a Deed of Covenant dated 23 January 2018 which sets out an undertaking to make annual payments until 2037.

The income is recognised when there is evidence of entitlement, receipt is probable and the amount can be measured reliably. For the Diageo donation, this is upon the receipt of the cash.

Income from Health and Social Care Departments

The UK Government supports the Trust by way of Health Grant funding agreements in place with the Health and Social Care Departments in England, Scotland, Wales and Northern Ireland up until 2022. In March 2021, the Chancellor, Rishi Sunak, announced a commitment to lifetime funding of the Health Grant to beneficiaries living in England.

The income is recognised when there is evidence of entitlement, receipt is probable and the amount can be measured reliably. For the Health and Social Care Departments Grants, this is upon the receipt of the cash.

Pension arrangements

The Trust operates a defined contribution pension scheme for employees. Contributions are paid into the group scheme, the assets of which are held in an independently administered fund. Contributions are charged to the statement of financial activities as they become payable. The Trust provides no other post-retirement benefits to its employees.

Charitable expenditure

All charitable expenditure is accounted for on an accruals basis and has been classified under the category headings, which aggregate all costs related to each category, as shown

in note 6. Where costs cannot be directly attributed to particular headings they have been allocated in proportion to the time spent by staff on work under each heading.

Notes to the financial statements for the year ended 30 September 2021 (continued)

Accounting policies (continued)

Grant-making

Grants payable are accounted for in full as liabilities of the charity when approved by the trustees.

Non-financial support costs

Beneficiary support costs comprise the direct costs, including staff, attributable to delivering the Trust's service of support to beneficiaries.

Governance

Governance costs cover expenditure on maintaining the constitutional and policymaking framework of the Trust and compliance with statutory requirements.

Irrecoverable VAT

Any irrecoverable VAT is charged to the statement of financial activities, or capitalised as part of the cost of the related asset, where appropriate.

Judgements and key sources of estimation uncertainty

Preparation of the financial statements requires management to make significant judgements and estimates. The items in the financial statements where these judgements and estimates have been made include the recognition of incoming donations and grants, and value of the Advances of Grants amounts falling due within, and after, one year.

Incoming grants and donations are considered on a year by year basis when discussions take place with Diageo plc and the four Health and Social Care Departments in the UK to consider the level of support needed for current beneficiaries. Future receipts are not anticipated within the financial statements as there is uncertainty as to the level of the receipts.

Advances of Grants are recovered by the Trust through deductions from future grants allocated to beneficiaries. Where possible, the Trust places a charge on property as security for the Advance and has further reduced the risk of the non-repayment of an Advance through an insurance policy held by the Trust. Based on these actions, in the judgement of the Trust's management the Advances as at the year-end are fully recoverable.

Notes to the financial statements for the year ended 30 September 2021 (continued)

2. Investment income

	2021 £000s	2020 £000s
Unrestricted		
Quoted investments and investment trusts	26	783
Listed unit trusts - UK regulated	371	-
Authorised common investment fund	1,768	1,789
Term deposit interest	-	5
	2,165	2,577
Restricted fund		
Term deposit interest	1	7
Total per Statement of Financial Activities	2,166	2,584

3. Diageo plc donation

On 12 July 2012 Diageo plc entered into a Deed of Covenant with the Thalidomide Trust which replaced earlier covenants executed by Guinness plc in 1995 and Diageo plc in 2000 and 2005.

The 2012 Covenant was reviewed during 2016 and a new Deed of Covenant was formally agreed in 2018. Under the new Covenant future increases in the Annual Grant paid to beneficiaries will be in line with the Retail Price Index (RPI.)

4. Investment management fees

The Investment Managers charge a fee for their services based upon an agreed percentage of the market value of the investments under management and a performance related fee.

The Investment Managers' fees charged for the year amounted to £392,000 (2020: £429,000).

In addition to the Investment Managers' fees, Trust costs relating to investment management were £55,000 (2020: £15,000), which comprised of unrestricted costs of £52,000 and restricted costs of £3,000. This is made up of £39,000 of investment consultancy services, £8,000 of staff time and £8,000 of independent portfolio evaluation and analysis.

5 Grant-making

Unrestricted Funds: General Grants

The trustees' grant-making policy has been:

For beneficiaries with capacity to manage their financial affairs

The trustees maintain a non-interest bearing nominee account for each beneficiary.

An Annual Grant is paid into the nominee account. A beneficiary has absolute entitlement to the balance in his or her nominee account and the balance is recognised as a liability of the Trust. Beneficiaries can instruct the Trust to make payments up to the balance in their nominee accounts from which they have entire discretion over the amount and frequency of the payments.

The Annual Grant is calculated with reference to the financial position of the Trust and each beneficiary's degree of disability, in accordance with the criteria applicable to distributions set out in the Diageo Deed of Covenant. The trustees reserve the right to amend the method of calculating the Annual Grant.

In addition to the Annual Grant, the trustees will consider requests for Major Advances (normally relating to significant one-off costs to meet mobility and housing needs), Short-Term Advances (to enable beneficiaries to make a transition in their housing arrangements where there are complex needs) and Emergency Advances (to meet unanticipated costs in the short term).

Where a Major, Short-Term or Emergency Advance has been made, future Annual Grants will be reduced by the amortisation of the Advance and an agreed annual fee to reflect the costs associated with making the Advance and the reduction in the Trust's investment assets as a result of the Advances. Major Advances will normally result in a reduction to the Annual Grants for a number of years whereas Short-Term and Emergency Advances will normally result in a reduction to the following year's Annual Grant.

For beneficiaries who lack capacity to manage their financial affairs

The trustees make payments to meet the needs of the beneficiary following discussion with the beneficiary's deputy or attorney officially registered with the Court of Protection to manage the beneficiary's financial affairs. Once funds have been transferred to the deputy or attorney for the benefit of the beneficiary, control of these funds passes absolutely out of the Trust. However, in line with Trust's policy on beneficiaries who lack capacity, there is a requirement for regular reporting on how these funds are utilised to meet the needs of the beneficiary and professional oversight.

Until such time as beneficiaries who lack capacity have a professional deputy in place, or where the appointed deputy has not fully complied with the regular reporting requirements, their Annual Grants are held in Beneficiary Memorandum Accounts as designated funds.

Notes to the financial statements for the year ended 30 September 2021 (continued)

5 Grant-making (continued)

All payments will always remain at the discretion of the trustees and will be allocated in accordance with the principles set out in the Trust Deed and in line with the Trust's policy on beneficiaries who lack capacity.

	2021		2020	
	Number of beneficiaries	Value of grants £000s	Number of beneficiaries	Value of grants £000s
Beneficiaries with capacity to manage their financial affairs	437	18,337	444	19,935
Beneficiaries who lack capacity to manage their financial affairs	13	907	15	1,012
Total of Grants	450	19,244	459	20,947

Restricted Funds: Departments of Health and Social Care Grants

The four UK Health and Social Care Departments provide funding for the Health Grants under an agreement for the period 2013 to 2022.

Health Grant funding is distributed in accordance with the Trust's existing distribution policy. The costs associated with administering the scheme are met from the funding. Details of Health Grant direct and indirect costs are set out in note 6. The level of costs charged has been determined by reference to factors such as the time spent on Health Grant related work (both administering and monitoring /reporting activities), together with appropriate proportions of operating costs.

Trust staff and beneficiary representatives meet with each of the Health and Social Care Departments on an ongoing basis. One of the key objectives of these reviews and the related negotiations is to actively manage the level of support requested from the four UK Health and Social Care Departments and the level and nature of the Health Grant fund expenditure such that there are no long term deficits, or surpluses, on the restricted Health Grant funds.

Health Grants by Country

	England	Scotland	Wales	N. Ireland	Total
£000s					£000s
Fund balances as at 1 October 2020	102	116	(280)	(111)	(173)
Incoming Health Grants	8,658	1,399	917	627	11,601
Health Grants Allocation	(8,304)	(1,326)	(934)	(548)	(11,112)
Interest income	1	-	-	-	1
Health Grant - Direct costs	(32)	(77)	(3)	(1)	(113)
Health Grants – Indirect costs	(250)	(40)	(19)	(11)	(320)
Fund balances as at 30 September 2021	175	72	(319)	(44)	(116)

Notes to the financial statements for the year ended 30 September 2021 (continued)

6 Trust costs and net income

		2021			2020		
	Note	Unrestricted £000s	Restricted £000s	Total £000s	Unrestricted £000s	Restricted £000s	Total £000s
Expenditure on raising funds:							
Investment management fees	4	392	-	392	429	-	429
Support costs (see below)		52	3	55	13	2	15
		444	3	447	442	2	444
Charitable activities:							
Grants	5,12	19,244	11,112	30,356	20,947	10,675	31,622
Net decrease in memorandum account balances	11,12	549	-	549	(1,183)	-	(1,183)
		19,793	11,112	30,905	19,764	10,675	30,439
Costs of grant making (see below)		94	32	126	84	31	115
Beneficiary support costs (see below)		736	327	1,063	770	271	1,041
Support costs (see below)		242	71	313	213	63	276
		20,865	11,542	32,407	20,831	11,040	31,871

2021								
	Staff and other HR costs	Admin and running costs	Legal, Professional and Audit fees	National Advisory Council	Campaigning Costs	Research & Development	Total	Restricted costs allocation
	£000s	£000s	£000s	£000s	£000s	£000s	£000s	£000s
Expenditure on raising funds:								
Investment management	5	8	38	-	-	-	52	3
Expenditure on charitable activities:								
Costs of grant-making	66	14	14	-	-	-	94	32
Beneficiary support costs	507	172	1	6	-	51	737	324
Other costs:								
- Governance & admin	131	24	23	23	-	-	201	
- New claims	27	9	-	-	-	-	36	
- Campaigns	3	-	-	-	2	-	5	
Total other costs	160	33	23	23	2	-	242	72
Total unrestricted costs	739	227	76	29	2	51	1124	
Restricted costs								
Beneficiary support costs	255	159	17	-	-	-	431	431
- Health Grant recharged								
Total costs - 2021	994	386	93	29	2	51	1,555	
Total costs - 2020 (see below)	943	267	53	22	23	140	1,448	

Notes to the financial statements for the year ended 30 September 2021 (continued)

6 Trust costs and net income (continued)

Comparative 2020	Staff and other HR costs	Admin and running costs	Legal, Professional and Audit fees	National Advisory Council	Campaigning Costs	Research & Development	Total	Restricted costs allocation
	£000s	£000s	£000s	£000s	£000s	£000s	£000s	£000s
Expenditure on raising funds:								
Investment management	5	8	-	-	-	-	13	2
Expenditure on charitable activities:								
Costs of grant-making	69	12	3	-	-	-	84	31
Beneficiary support costs	473	139	14	4	-	140	770	271
Other costs:								
- Governance & admin	89	19	18	18	-	-	144	
- New claims	29	2	3	-	-	-	34	
- Campaigns	11	1	-	-	23	-	35	
Total other costs	129	22	21	18	23	-	213	63
Total unrestricted costs	677	181	38	22	23	140	1,081	
Restricted costs								
Beneficiary support costs - Health Grant recharged	266	86	15	-	-	-	367	367
Total costs – 2020	943	267	53	22	23	140	1,448	
Total costs - 2019	839	282	102	25	52	89	1,389	

Net income for the year is stated after charging:

	2021 £000s	2020 £000s
Depreciation (2020 included a profit on disposal of £7,600)	24	21
Audit Fees	26	24

Notes to the financial statements for the year ended 30 September 2021 (continued)

7 Trustee and employee information

The monthly average number of persons employed by the Trust during the year was 18 (2020: 18).

Staff costs (for the above persons)	2021 £000s	2020 £000s
Gross salaries and wages	720	708
Social security costs	78	71
Employer pension contributions	70	64
Other employee benefits	32	26
	900	869

The number of employees whose total emoluments (i.e. salary and taxable benefits) exceeded £60,000 were:

	2021 Number	2020 Number
£60,001 - £70,000	1	1
£70,001 - £80,000	1	2
£80,001 - £90,000	1	-
£100,001 - £110,000	-	1
£110,001 - £120,000	1	-

Pension contributions towards a money purchase scheme paid in the year for the above staff whose total emoluments exceeded £60,000 amounted to £30,000 (2020: £29,000).

No remuneration was paid to the trustees of The Thalidomide Trust Company Ltd (2020: £nil). Travel and subsistence expenses of £2,500 (2020: £1,900) were reimbursed to 4 (2020: 4) trustees of The Thalidomide Trust Company Ltd during the year.

The total remuneration and benefits received by the Trust's key management personnel was £270,000 (2020: £254,000) for 3 employees (2020: 3).

Notes to the financial statements for the year ended 30 September 2021 (continued)

8 Tangible assets

Tangible assets comprise the following:

	Motor Vehicles £000s	Furniture & equipment £000s	Building £000s	Total £000s
Cost				
At 1 October 2020	52	5	465	522
Additions	-	12	-	12
Disposals	-	(5)	-	(5)
At 30 September 2021	52	12	465	529
Accumulated depreciation				
At 1 October 2020	10	5	165	180
Charged	13	1	10	24
Disposals	-	(5)	-	(5)
At 30 September 2021	23	1	175	199
Net book value				
At 30 September 2021	29	11	290	330
At 30 September 2020	42	-	300	342

All tangible fixed assets are unrestricted.

9 Investments

	2021 £000s	2020 £000s
Listed Investments		
UK Equities	-	15,384
US Equities	-	1,221
Europe Equities	-	808
Other Equities	-	2,598
Unlisted investments		
Global Unit Trusts (Equities)	137,236	98,046
Global Unit Trusts (Fixed Income)	30,631	29,767
UK Charity Funds	17,461	2,541
Open Derivatives Positions	-	(35)
Cash held for investments (including accrued investment income)	806	1,435
Total per Balance Sheet	186,134	151,765

All investments are held as unrestricted funds.

Notes to the financial statements for the year ended 30 September 2021 (continued)

9 Investments (continued)

The movement on investments in the year was as follows:

	2021 £000s	2020 £000s
Market value b/fwd 1 October 2020	151,765	167,977
Less: Disposal proceeds/ share exchanges	(45,463)	(9,370)
Add: Purchases at cost/share exchanges	40,954	7,316
Realised and unrealised gains/(losses)	39,506	(13,217)
Increase/(decrease) in cash held for investment (including accrued investment income)	(628)	(941)
Market value at 30 September 2021	186,134	151,765
Historical cost at 30 September 2021	142,189	147,142

The market value of investments has recovered this year, after dropping considerably in 2019/20 due to the effect of the pandemic on the stock markets. In October 2020, trustees moved £30m of funds into a new ESG fund with Legal & General Investment Management (LGIM). Following this change, the remaining directly-held equities with Schroders reached a size where it was deemed preferable to move the portfolio to a pooled approach rather than segregated. Therefore, these remaining £11m of UK equities were moved to a holding in the SUTL Cazenove Charity Equity Value Fund.

The trustees believe that the carrying value of the listed investments is supported by the underlying net assets.

Derivatives

Derivatives are initially recognised at transaction value and subsequently measured at their settlement value. The following table shows derivatives in relation to investments.

	2021 £000s	2020 £000s
Cash offset index futures	-	-
Open currency forward agreements	-	(35)
Equities Futures	-	-
Open Derivatives Positions	-	(35)

Notes to the financial statements for the year ended 30 September 2021 (continued)

10 Subsidiary

ValidATE Trust was established on 7 August 2019 as a Private Limited Company by guarantee. The Thalidomide Trust has taken advantage of the exemption under section 24.13A of the Charities SORP, and not consolidated the results of ValidATE Trust in the Group financial statements.

All costs associated with the establishment of the company were incurred by the Trust and recharged to the company.

At the 30 September 2021, ValidATE Trust owed the parent company, The Thalidomide Trust, £33,000 (2020: £51,000).

The results of ValidATE Trust for the period ended 30 September 2021 are shown below.

Audited Accounts are filed with the Registrar of Companies.

	2021
	£
Turnover and other income	23,920
Cost of sales and expenses	(21,845)
Profit for the year	2,075
Profit and loss reserves	(19,629)

11 Trust Fund including comparatives

	Unrestricted funds			
	Designated Beneficiary Memorandum Accounts £000s	General Fund £000s	Restricted Fund £000s	Total Trust Funds £000s
Balance as at 1 October 2020	3,802	137,160	(173)	140,789
Net incoming/(outgoing) resources as per Statement of Financial Activities	-	33,790	57	33,847
Adjustment for net increase in beneficiary memorandum accounts (note 12)	(549)	549	-	-
Balance as at 30 September 2021	3,253	171,499	(116)	174,636
	Note 12		Note 5	

Notes to the financial statements for the year ended 30 September 2021 (continued)

11 Trust Fund including comparatives (continued)

	Unrestricted funds			
	Designated Beneficiary Memorandum Accounts £000s	General Fund £000s	Restricted Fund £000s	Total Trust Funds £000s
Fixed Assets				
Tangible	-	330	-	330
Investments	2,732	183,402	-	186,134
Current Assets				
Debtors and Prepayments	-	100	-	100
Advance of Grants	-	1,963	-	1,963
Cash at Bank and in Hand	521	2,742	4,985	8,248
Creditors: amounts falling due within one year				
Beneficiary nominee accounts	-	(16,807)	(5,101)	(21,908)
Creditors and accrued expenses	-	(231)	-	(231)
Balance as at 30 September 2021	3,253	171,499	(116)	174,636
	Note 12		Note 5	

	Unrestricted funds			
	Beneficiary Memorandum Accounts £000s	General Fund £000s	Restricted Fund £000s	Total Trust Funds £000s
Comparatives				
Balance as at 1 October 2019	2,619	155,529	(291)	157,857
Net incoming/(outgoing) resources as per Statement of Financial Activities	-	(17,187)	118	(17,069)
Adjustment for net increase in beneficiary memorandum accounts	1,183	(1,183)	-	-
Balance as at 30 September 2020	3,802	137,160	(173)	140,789
	Note 12		Note 5	

Notes to the financial statements for the year ended 30 September 2021 (continued)

11 Trust Fund including comparatives (continued)

Comparatives	Unrestricted funds		Restricted Fund £000s	Total Trust Funds £000s
	Beneficiary memorandum Accounts £000s	General Fund £000s		
Fixed Assets				
Tangible	-	342	-	342
Investments	3,180	148,585	-	151,765
Current Assets				
Debtors and Prepayments	-	103	-	103
Advance of Grants	-	2,373	-	2,373
Cash at Bank and in Hand	622	1,513	3,894	6,029
Creditors: amounts falling due within one year				
Beneficiary nominee accounts	-	(15,351)	(4,067)	(19,418)
Creditors and accrued expenses	-	(405)	-	(405)
Balance as at 30 September 2020	3,802	137,160	(173)	140,789
	Note 12		Note 5	

12 Beneficiary accounts

	Beneficiary memorandum accounts £000s	Beneficiary nominee accounts £000s	Beneficiary Health Grant accounts £000s	Total 2021 £000s	Total 2020 £000s
As at 1 October 2020					
Balance Sheet- Beneficiary Nominee Accounts		15,351	4,067	19,418	18,442
Balance Sheet- Beneficiary Memorandum Accounts	3,802				
Annual Grant Allocations	910	18,334		19,244	20,947
Health Grant Allocations			11,112	11,112	10,721
Payments from Beneficiary Accounts	(1,459)	(16,878)	(10,078)	(28,415)	(29,509)
Transfers between Nominee and Memorandum Accounts	-	-			
Adjustment for net decrease/ (increase) in Beneficiary Memorandum Accounts				549	(1,183)

As at 30 September 2021:

Balance Sheet- Beneficiary Nominee Accounts	16,807	5,101	21,908	19,418
Balance Sheet- Beneficiary Memorandum Accounts	3,253			

Note 11

Notes to the financial statements for the year ended 30 September 2021 (continued)

12 Beneficiary accounts (continued)

Beneficiary Memorandum Accounts are all designated funds and include: accounts for beneficiaries who lack capacity to manage their financial affairs (as detailed at note 5) and backdated grants allocated to beneficiaries. On the death of a beneficiary, any funds held in Memorandum Accounts revert to the General fund to be used for the benefit of the wider community.

Beneficiary nominee accounts include the grant funds to which a beneficiary has absolute entitlement and which have not been requested by beneficiaries at the year-end (as detailed in note 5).

Beneficiary Health Grant accounts include the Health Grant funding made available, but not requested by beneficiaries (as detailed in note 5).

13 Taxation

The Trust is a registered charity, and as such is entitled to certain tax exemptions on income and profits from investments, and surpluses on any trading activities carried on in furtherance of the charity's primary objectives, if these profits and surpluses are applied solely for charitable purposes.

During the current and prior years, all distributions to beneficiaries were paid under the terms of Statutory Instrument 2004 No 1819, which allows distributions from the Trust to be paid free of income tax, and therefore no income tax liability arose.

14 Pension obligations

Defined contribution scheme

Permanent staff are eligible to receive a pension provision equivalent to 10% of gross salary under a defined contribution scheme. During the year employer contributions to this scheme amounted to £70,000 (2020: £67,000).

At the end of the year other creditors and accruals included £8,900 (2020: £9,600) payable in respect of employer pension contributions.

15 Debtors

	Total funds 2021 £000s	Total funds 2020 £000s
Advances of Grants		
amounts falling due within one year	625	548
amounts falling due after one year	1,338	1,825
Other debtors	32	51
Prepayments and accrued income	68	52
Total	2,063	2,476

Notes to the financial statements for the year ended 30 September 2021 (continued)

15 Debtors (continued)

As set out in note 5, the trustees will consider requests for Major Advances and Emergency Advances. The Advances consist of Major Advances and Emergency Advances balances as at 30 September 2021. Advances are recoverable from future Annual Grant allocations. Emergency Advances are recoverable within one year, Major Advances are recoverable up to a maximum of ten years.

16 Creditors

	Total funds 2021 £000s	Total funds 2020 £000s
Creditors: amounts falling due within one year		
Beneficiary nominee accounts (note 12)	21,908	19,418
Other creditors and accruals	231	405
Total	22,139	19,823

17 Net Debt Disclosure

	At 1 October 2020	Cash-flows	Other non- cash changes	At 30 September 2021
	£	£	£	£
Cash	6,029	2,219	-	8,248
Cash held for investment	1,435	(629)	-	806
Total	7,464	1,590	-	9,054

18 Related Party Transactions

Other than expenses paid to Trustees (see note 7), there were no related party transactions during the year.

During the period, the charity made payments for expenditure of its subsidiary, ValiDATE Trust, of £8,000 (2020: £70,000).

At the year end, the Trust was owed £33,000 (2020: £51,000) from the ValiDATE Trust. This balance is presented within other debtors.

There is no parent undertaking. The ultimate controlling party is The Thalidomide Trust Company Ltd.

Notes to the financial statements for the year ended 30 September 2021 (continued)

19 Comparatives for Statement of Financial Activities

Comparatives	Note	Unrestricted Funds £000s	Restricted Funds £000s	Total Funds 2020 £000s
Income from:				
Diageo donations	3	14,605	-	14,605
Health Department Grants	5	-	11,153	11,153
Investment income	2	2,577	7	2,584
Other income		122	-	122
Total		<u>17,304</u>	<u>11,160</u>	<u>28,464</u>
Expenditure on:				
Raising funds (solely investment management fees)	6	(442)	(2)	(444)
Charitable activities	6	(20,831)	(11,040)	(31,871)
Total		<u>(21,273)</u>	<u>(11,042)</u>	<u>(32,315)</u>
Net gains/(losses) on investments	9	(13,217)	-	(13,217)
Net income (expenditure)		<u>(17,186)</u>	<u>118</u>	<u>(17,068)</u>
Reconciliation of Funds				
Fund balances brought forward At 1 October 2019	11	158,148	(291)	157,857
Fund balances carried forward at 30 September 2020	11	<u>140,962</u>	<u>(173)</u>	<u>140,789</u>