# 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
	Katy Sagoe - Director of Health & Wellbeing Suzanne Lluch - Finance Director
Medical Advisers	Suzanne Lluch - Finance Director
Medical Advisers	Suzanne Lluch - Finance Director Dr Dee Morrison MB ChB (to 31 May 2023)
Medical Advisers	Suzanne Lluch - Finance Director
Medical Advisers	Suzanne Lluch - Finance Director Dr Dee Morrison MB ChB (to 31 May 2023) Dr Susan Brennan MBChB MRCGP
Medical Advisers Chair of NAC	Suzanne Lluch - Finance Director Dr Dee Morrison MB ChB (to 31 May 2023) Dr Susan Brennan MBChB MRCGP Dr Helen Smith MBChB MRCGP

Investment Managers	BlackRock 12 Throgmorton Avenue London EC2N 2DL	TwentyFour Asset Management 8 <sup>th</sup> Floor The Monument Building 11 Monument Street London EC2R 8AF
	Schroders Investment Manag 1 London Wall Place London Wall London EC2Y 5AU	ement Limited
	Legal & General Investment N One Coleman Street London EC2R 5AA	Vanagement
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 str	rategic 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 the 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**

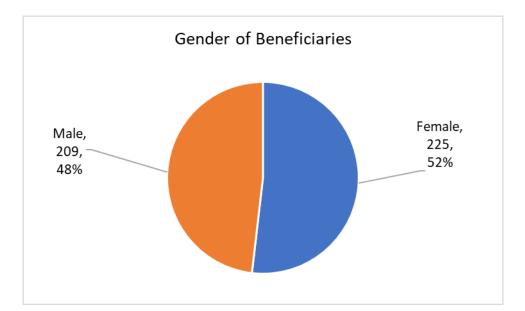
The Trust has responsibility for assessing new applications to become beneficiaries of the Trust and has established a robust procedure for assessing new applications, drawing on international evidence and utilising the diagnostic algorithm, valiDATE, which was one of the key outputs of the WHO conference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

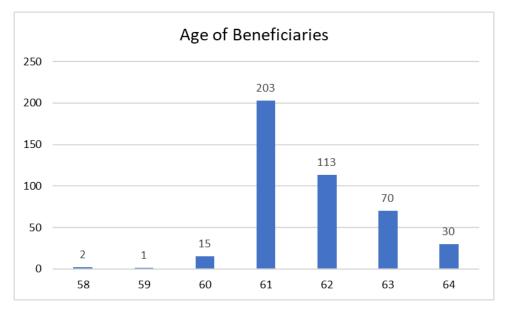
During the year, the Trust received 30 completed applications from individuals who thought they may be entitled to become beneficiaries, however, no applicants met the necessary criteria for acceptance in the twelve-month reporting period.

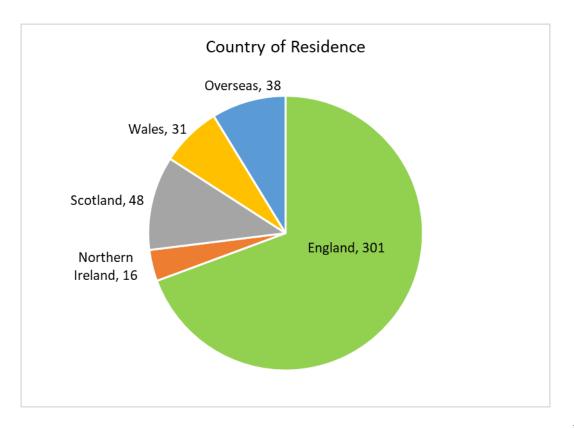
It is with regret that the Trustees report the deaths of four beneficiaries during the year.

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.







#### **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.	<ul> <li> created our Specialist Mental Health</li> <li>Network and launched this in Summer</li> <li>2023.</li> </ul>

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 basis<sup>1</sup> 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

<sup>&</sup>lt;sup>1</sup> 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: <a href="http://www.frc.org.uk/auditorsresponsibilities">www.frc.org.uk/auditorsresponsibilities</a>. 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
<b>Expenditure on:</b> Raising funds (solely investment management fees) Charitable activities	6 6	(316) (54,514)	- (13,254)	(316) (67,768)	(417) (33,655)
Total		(54,830)	(13,254)	(68,084)	(34,072)
Net gains/(losses) on investments <b>Net income (expenditure)</b>	9	13,273 (24,930)	(80)	13,273 (25,010)	(13,793) (16,826)
Reconciliation of funds Fund balances brought forward at 1 October 2022/2021 Fund balances carried forward	11	157,244	566	157,810	174,636
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	Total funds
		30/09/2023	30/09/2022
		£000s	£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

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

#### 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.

### **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.

2.	Investment income

Unrestricted	2023 £000s	2022 £000s
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
Restricted fund	4,886	3,136
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	Number of beneficiaries	Value of grants
		£000s		£000s
Beneficiaries with capacity to manage their financial affairs Beneficiaries who lack capacity	414	49,207	421	19,321
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.

	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

#### Health Grants by Country

# 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

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 - Health Grant recharged	301	133	26	-	-	-	459	459
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	

# 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	2022
	£000s	£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 <b>1</b>	1
£70,001 - £80,000 <b>0</b>	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	2022
	£000s	£000s
Unlisted investments		
Equities	103,634	143,628
Fixed Income	42,090	25 <i>,</i> 698
Cash held for investments	893	1,265
(including accrued investment income)		
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 f	unds		
	Designated			
	Beneficiary	General	Restricted	Total
	Memorandum	Fund	Fund	Trust
	Accounts			Funds
	£000s	£000s	£000s	£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

0)100 100,010	100	
Note 12	Note 5	
NOLE 12	NOLE 3	

	Unrestricted funds			
	Designated			
	Beneficiary	General	Restricted	Total
	Memorandum	Fund	Fund	Trust
	Accounts			Funds
	£000s	£000s	£000s	£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	

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# **11** Trust Fund including comparatives (continued)

	Unrestricted f			
Comparatives	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	349	(349)	-	-
Balance as at 30 September 2022	3,602	153,642	566	157,810
	Note 12		Note 5	

	Unrestricted	funds		
Comparatives	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	

#### **12** Beneficiary accounts

	Beneficiary	Beneficiary	Beneficiary Health	Total	Total
	memorandum	nominee	Grant	2023	2022
	accounts	accounts	accounts		
	£000s	£000s	£000s	£000s	£000s
As at 1 October 2021					
Balance Sheet- Beneficiary Nominee Ac	counts	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				

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	10003	10003
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

#### **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	Note	Unrestricted Funds £000s	Restricted Funds £000s	Total Funds 2022 £000s
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
		18,400	12,039	51,039
Expenditure on: Raising funds (solely investment				
management fees)	6	(415)	(2)	(417)
Charitable activities	6	(21,700)	(11,955)	(33,655)
	Ũ	(21,700)	(11,555)	(33,633)
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)
nee meenie (expenditure)		(17,500)	002	(10,020)
Reconciliation of Funds				
Fund balances brought forward	11	174,752	(116)	174,636
At 1 October 2021			, , , , , , , , , , , , , , , , , , ,	·
Fund balances carried forward				
at 30 September 2022	11	157,244	566	157,810
•			· · · · · · · · · · · · · · · · · · ·	