

HISTIOCYTOSIS UK

KNOWN AS

HISTIO UK

ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2023

Trustees	Mir A Kontoyannis, Chair Prof. P Beverley Dr V Nanduri Mr P Bienenstock Prof. M Collin Prof. C Booth Dr R Tattersall
Other officers	Lynn Jackson, Executive Director
Charity number	1158789
Principal address	PO Box 159 Liskeard Cornwall PL14 9DQ
Independent examiner	TC Group 33 Boston Road Holbeach Spalding Lincolnshire PE12 7LR
Bankers	CAF Bank Limited 25 Kings Hill Avenue Kings Hill West Malling Kent ME19 4JQ

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The trustees present their report and financial statements for the year ended 31 March 2023.

## Objectives and activities

### Public benefit

- The object of the CIO is the relief of sickness and preservation of good health among patients affected by histiocytic diseases their families and carers, in particular but not exclusively by:

- (i) the promotion and furtherance of scientific research into the physiology and pathology of histiocytes and the aetiology of histiocytic diseases, the useful results of which will be disseminated for the public benefit;
- (ii) the development of more accurate means of diagnosis, improved protocols for management of patients and ultimately measures for prevention of histiocytic diseases;
- (iii) the provision and dissemination of information, education and knowledge in support of patients and families affected by the disease to include the medical professions and general public;

- (iv) collaboration with interested individuals and organisations.

The Trustees confirm that they have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the Charity's aims and objectives and in planning future activities and setting the grant making policy for the year.

The Charity carries out these objectives by focusing on these areas through which we achieve our strategic priorities of maintaining a stable programme and the continued funding of vital research. The benefits of the Charity's work are the development of future research, the dissemination of research findings, the development of new therapies and the funding of on-going research with the goal being able to inform sufferers, their carers and families.

The trustees confirm that they have complied with the requirements of section 17 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission for England and Wales.

## Financial Report

### Investment policy and objectives

The Charity's policy at present is to invest in low-risk and reasonably liquid assets, so that funds are available to meet any unforeseen needs that may arise, for example, as a consequence of meeting activities.

As far as possible, the Charity seeks to follow an ethical investment strategy that precludes investing in any company whose activities may have an adverse impact on the underlying beneficiaries of the charity. While striving for the highest ethical standards, the Charity will adhere to the Charity Commission's rule that we maximise the income of the charity without exposure to undue risk.



**Financial review**

The Chairman regularly reviews the reserves of the charity to ensure that sufficient liquid funds are available to the Charity to meet its ongoing obligations. The reserves throughout the accounting period have been adequate to fulfil this objective.

**Income & Expenditure Summary**

The 2022-2023 income was steady against the previous financial year. Charities in general suffering from the continued downturn in the cost of living raising concerns in the "cost of giving" in this economic climate.

We thank all of our generous donors, the individuals, community groups, schools, corporate supporters, Charities and Foundations that continued their support and reflects the excellent participation, drive and generosity of our community fundraisers, supporters, families and committed individuals that have been able to assist us maintain the Charity.

**Grant Awards**

Histio UK are very pleased to advise that two Research Grant Awards have been made during the period to value of £72,373. Dr Mark Bishston & his team for Liquid biopsy for the identification of malignancy associated haemophagocytic lymphohistiocytosis (HLH) and Dr E.P. Buddingh & her team for HLH Inflammatory Profile as a Predictor for stem cell transplant Outcome in children (HIPPO) study: cytokine dynamics to identify druggable targets and improve outcome.

**Grants Received**

We are incredibly pleased to announce that during 2022 Histio UK have been successful in our application to the National Lottery Community Fund.

The funders awarded Histio UK £9,900 for engagement of an Outreach Officer to help improve awareness and social media engagement.

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**Chairman's Statement****Financial**

We recognise that this year our Charity income reflects the strain on all our accounts and personal budgets. The continuing generosity of our donors and supporters of time, energy and funds has enabled the Charity work to continue in these challenging times.

As we reflect on this past year of operation and the amazing support that we have received, the Charity recognises that the current economic climate effects not only us, but all of our Histo Community and beyond remaining a very difficult period for all.

Despite reduced income we have been able to continue our Information Support services and Partnership Projects.

We are very pleased to have continued and further developed our various Histiocytic information guides and social media platforms allowing us to engage further with our Patients, Parents and Supporters.

In association with our partners, we will continue to support histiocytic professionals, patients and families with up-to-date information on these devastating disorders as it becomes available.

Thank you all.

**Partnerships**

**Hi-HASC- Haemophagocytic Lymphohistiocytosis (HLH) Across Specialty Collaboration**  
 Histo UK provides website administrative support to this amazing group.

**UK Histo Registry –**

Histo UK provides website administration to this established registry program.

**PPPIE Panel – Patient, Parent, Public Involvement & Engagement Panel**

Histiocytosis UK is committed to meaningful patient and public involvement and engagement for and on behalf of not only its own Grant Fund Awards but to appraise those of other Researchers and or Organisations in the field of research with priority to those of Histiocytic diseases.

Our vision with regards to patient, parent and public involvement and engagement is-

“to establish a culture within Histiocytosis UK where our community has the skills and resources to optimise and deliver patient and public involvement and engagement and it is integrated in to our ways of working and throughout the research we fund and appraise”

Histiocytosis UK has, in consultation with researchers, public contributors and involvement professionals, identified 6 aims that will guide Histiocytosis UK and its engagement programme to work towards it's vision that No one should die of Histiocytosis:

- Ensure our research community incorporates patient and public involvement and engagement throughout research.
- Incorporate relevant involvement throughout our funding processes.
- Lead by example in our involvement and engagement practice.
- Strengthen involvement and engagement practice of Histo UK's Patient, Parent & Public Involvement Engagement Panel.
- Inspire and encourage inclusive, innovative, diverse and creative patient, parent and public involvement and engagement.
- Improve the knowledge sharing of patient, parent and public involvement and engagement.

**Histiocytosis Hellas & The Nikolas Symposium**

Histo UK continues to maintain a close working relationship with Histiocytosis Hellas (Artemis Association) and the scientific forum of the Nikolas Symposium.

**The Histiocyte Society**

The HS is the organisation representing clinical and research professionals in the field of Histiocytic disorders. They have agreed to share their virtual educational programme with us during the 2022-2023 period.



## Awareness

***Histiocytosis UK 2022 – Virtual Forum on 17th November 2022***

Building on previous years, the format of the 2022 programme for the Virtual Forum included the delivery of Abstracts, enabling a platform for not only established specialists but introduced emerging new talent in the field of Histiocytic disorders to a specialists audience from the UK and around the world.

**Haemophagocytic lymphohistiocytosis (HLH) ADULT - Host: Prof. Claire Booth**

**Dr. Anupama Rao, Paediatric Haematology Consultant, GOSH & Dr. James Clark, Haematology Spr, GOSH**  
The National Paediatric HLH MDT – Audit.

**Dr. Austen Worth, Paediatric Immunology at Great Ormond Street Hospital for Children and an associate professor in molecular immunology at UCL.**  
Novel therapies for HLH.

**Prof. Claire Booth, Mahboubian Professor in Gene Therapy and Paediatric Immunology & Consultant in Paediatric Immunology, Great Ormond Street Hospital.**  
Small molecules to treat XLP and XIAP deficiency.

**HLH & Hyperinflammatory syndrome – Hosts: Dr. Jessica Manson & Dr Rachel Tattersall**

**Abstracts presented by:**

**Dr. Betty Gratton - University College London Hospitals NHS Foundation Trust - Primary HLH in adults; genetic testing and use of Ruxolitinib.**

**Dr. Haris Khan - Frimley Health NHS Trust - When it's not just Typhoid fever**

**Dr. Thomas Nadin - Sheffield Teaching Hospitals NHS Foundation Trust - An evaluation of the causes and outcomes of haemophagocytic lymphohistiocytosis (HLH) in Sheffield Teaching Hospitals (2016 to 2021)**

**Speakers**

**Dr. Miriam Cox - Rheumatology Trainee, Sheffield - The HiHASC guideline for the investigation of HLH in adults.**

**Dr. Sam Clark - Consultant in ICU and anaesthetics, UCLH - The cardiac implications of HLH.**

**Dr. Grant Schüert - Paediatric Rheumatologist, Cincinnati Children's Hospital - HLH/MAS lessons learnt from rheumatological practice.**

**Plans for the future**

Histo UK, will remain at the forefront in challenging these devastating disorders, we will continue to build on the transfer of information and knowledge available nationally and international through our committee structure to parents, patients and medical professionals.

**Structure, governance and management**

**Organisational structure**

Histiocytosis UK is a registered charity, number 1158789, and is constituted as a charitable incorporated organisation in England and Wales.

The Charity actively fundraises and seeks to continue the charitable work desired by the donor through the careful stewardship of its existing resources.

At the annual Trustees' meetings, the Trustees agree the broad strategy and areas of activity for the Charity, including consideration of grant making, investment, reserves and risk management policies and performance.

The day-to-day administration of grants and the processing and handling of applications prior to consideration by the Charity is delegated to the Executive Director.

The Charity's Independent Scientific Review Board consider all applications against agreed criteria prior to making recommendation to the Charity on funding grants. The SRB review all applications received in response to calls for proposals.

**The Chair of the SRB for 2022-2023**

Professor Matthew Collin, BM, BCh, DPhil, MRCP, FRCPATH.

**Vice-Chair**

Professor Peter Beverley MBBS, DSc, FMedSci.

The Trustees review on a regular basis both to recruit new Trustee(s) for their experience, empathy and knowledge of the charity and to keep the skills and composition of the Trustee body and succession planning under review.

As we move into our new financial year Trustees will retire at the end of their term of office with the Charity. As always, we will take this opportunity to review our Governance structure and assess the benefits of utilising any opportunities that may be derived from advisory boards allowing us to more fully support the Executive Director in forthcoming projects and initiatives and at the same time focus on our strengths.

**Fundraising Regulation**

The Charity is registered with the Fundraising Regulator and is in full compliance with its requirements. The Charity adheres to the key principles and behaviours in that the work of its fundraising will be Legal, Open, Honest and Respectful.

**Risk management**

The Trustees have considered the major risks to which the charity is exposed and have reviewed those risks and established systems and procedures to manage those risks.

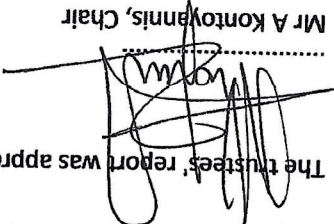
The Trustees consider variability of investment returns.

Our thanks

The Charity wishes to express its gratitude to all our volunteers for their fundraising activities, technical skills, and participation in virtual and physical events that have taken place throughout the country in this difficult year.

Our thanks to our Corporate donors including those with match funding programmes which encourage our supporters with their own fundraising activities.

The Trustees' report was approved by the Board of Trustees.

  
.....  
Mr A Kontoyannis, Chair  
Trustee  
Dated: 12/06/2023

The trustees are responsible for preparing the Trustees' 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 trustees 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 application of resources of the charity for that year.

In preparing these financial statements, the trustees are required to:

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

The trustees are responsible for keeping sufficient accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them 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. They are 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.



**HISTIOCYTOSIS UK**  
**HISTIO UK**  
**INDEPENDENT EXAMINER'S REPORT**  
**TO THE TRUSTEES OF HISTIOCYTOSIS UK**

I report to the trustees on my examination of the financial statements of Histiocytosis UK (the charity) for the year ended 31 March 2023.

**Responsibilities and basis of report**

As the trustees of the charity you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011 (the 2011 Act).

I report in respect of my examination of the charity's financial statements carried out under section 145 of the 2011 Act. In carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

**Independent examiner's statement**

Your attention is drawn to the fact that the charity has prepared financial statements in accordance with Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) in preference to the Accounting and Reporting by Charities: Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulations but has now been withdrawn.

I understand that this has been done in order for financial statements to provide a true and fair view in accordance with Generally Accepted Accounting Practice effective for reporting periods beginning on or after 1 January 2015.

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

- 1 accounting records were not kept in respect of the charity as required by section 130 of the 2011 Act; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the financial statements to be reached.

Christopher McKenna ACA



TC Group  
33 Boston Road  
Holbeach  
Spalding  
Lincolnshire  
PE12 7LR

Dated: 27/6/23

**HISTIOCTOSIS UK**  
**HISTIO UK**  
**STATEMENT OF FINANCIAL ACTIVITIES**  
**INCLUDING INCOME AND EXPENDITURE ACCOUNT**  
**FOR THE YEAR ENDED 31 MARCH 2023**

	Notes	Unrestricted funds 2023 £	Restricted funds 2023 £	Total Unrestricted funds 2023 £
<b>Income from:</b>				
Donations and legacies	3	141,526	9,900	151,426
Investments	4	1,704	-	1,704
<b>Total income</b>		<b>143,230</b>	<b>9,900</b>	<b>153,130</b>
<b>Expenditure on:</b>				
Raising funds	5	1,073	-	1,073
Charitable activities	6	153,783	9,900	163,683
<b>Total resources expended</b>		<b>154,856</b>	<b>9,900</b>	<b>164,756</b>
<b>Fund balances at 1 April 2022</b>		<b>(11,626)</b>	<b>-</b>	<b>(11,626)</b>
<b>Fund balances at 31 March 2023</b>		<b>427,803</b>	<b>-</b>	<b>427,803</b>
		<b>416,177</b>	<b>-</b>	<b>416,177</b>

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

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**HISTIOCYTOSIS UK  
HISTIO UK  
BALANCE SHEET  
AS AT 31 MARCH 2023**

	Notes	2023	2022	£
<b>Fixed assets</b>				
Tangible assets	10	1,269		£
Current assets				
Debtors	11	855	762	
Cash at bank and in hand		417,306	428,187	
<b>Creditors: amounts falling due within one year</b>				
	12	(3,253)	(3,039)	
<b>Net current assets</b>		414,908		
<b>Total assets less current liabilities</b>		416,177	427,803	
<b>Income funds</b>				
Unrestricted funds		416,177	427,803	
		416,177	427,803	

The financial statements were approved by the Trustees on 12/06/2023

Trustee  
Mr A Kontoyannis, Chair

**1 Accounting policies**

**1.1 Accounting convention**

The financial statements have been prepared in accordance with the charity's governing document, the Charities Act 2011 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)". The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities applying FRS 102 Update Bulletin 1 not to prepare a Statement of Cash Flows.

The financial statements 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 the Statement of Recommended Practice for charities applying FRS 102 rather than the version of the Statement of Recommended Practice which is referred to in the Regulations but which has since been withdrawn.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value. The principal accounting policies adopted are set out below.

**1.2 Going concern**

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

**1.3 Charitable funds**

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

**1.4 Income**

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.



**1 Accounting policies** (Continued)

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

**1.5 Expenditure**

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

**Raising funds**

These are costs incurred in attracting voluntary income, the management of investments and those incurred in trading activities that raise funds.

**Charitable activities**

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

**1.6 Tangible fixed assets**

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Office equipment

33% reducing balance

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in net income/(expenditure) for the year.

**1.7 Impairment of fixed assets**

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

**1.8 Cash and cash equivalents**

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

**1 Accounting policies**

**1.9 Financial instruments**

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

**Basic financial assets**

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

**Basic financial liabilities**

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

**Derecognition of financial liabilities**

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

**1.10 Employee benefits**

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2023

2 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

3 Donations and legacies

	Unrestricted funds	Restricted funds	Total Unrestricted funds
2023	2023	2023	2023
£	£	£	£
Donations and gifts	141,526	9,900	151,426
Donations and gifts	141,526	9,900	151,426
Donations and gifts	141,401	9,900	151,301
Donations	125	-	125
Gift aid tax reclaimed	141,526	9,900	151,426
Investments	141,526	9,900	151,426
Interest receivable	141,526	9,900	151,426

4 Investments

Unrestricted funds	Unrestricted funds
2023	2022
£	£
1,704	34



## 5 Raising funds

General fundraising and event expenses

## 6 Charitable activities

Grant funding of activities (see note 7)



**10 Tangible fixed assets**

[illegible]

13 Analysis of net assets between funds

Unrestricted funds	Restricted funds	Total	Unrestricted funds
2023	2023	2023	2022
£	£	£	£
Fund balances at 31 March 2023 are represented by:			
Tangible assets			
Current assets/(liabilities)			
1,269	-	1,269	1,893
414,908	-	414,908	425,910
416,177	-	416,177	427,803

14 Related party transactions

There were no disclosable related party transactions during the year (2022 - none).