

FANCONI HOPE

Independent Examiner's Report to the Trustees of

Fanconi Hope

For the year ended 30 April 2024

I report on the accounts of the charity for the year ended 30 April 2024, which are set out on pages 6 to 7.

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the Charities Act,
- to follow the procedures laid down in the general Directions given by the Charity Commission (under section 145 (5)(b) of the 2011 Act, and
- to state whether particular matters have come to my attention.

Basis of independent examiner's statement

My examination was carried out in accordance with general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the statement below.

Independent examiner's statement

In connection with my examination, no matter has come to my attention

1. which gives me reasonable cause to believe that in, any material respect, the requirements:

- to keep accounting records in accordance with section 130 of the Charities Act; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Charities Act

have not been met ; or

2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



Jennifer de Clercq
Smithe & Co Limited
Chichester Enterprise Centre
Terminus Road
Chichester
West Sussex
PO19 8FY

Date: 13 February 2025

FANCONI HOPE

STATEMENT OF ACCOUNTS

FOR THE YEAR ENDED 30 APRIL 2024

FANCONI HOPE

INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 30 APRIL 2024

<u>2023</u>		<u>2024</u>	
	<u>RECEIPTS</u>		
26,385.98	Donations	49,209.81	
10,840.00	Grant	13,408.00	
1,143.75	Gift Aid	6,885.65	
<u>381.80</u>	Bank interest	<u>1,393.77</u>	
38,751.53			70,897.23
	<u>PAYMENTS</u>		
	<u>Charitable Activities</u>		
10,300.00	FA Europe	20,060.00	
2,378.70	Conference costs	6,452.09	
31,512.78	Research costs	23,587.00	
<u>300.00</u>	Subscriptions	<u>150.00</u>	
44,491.48			50,249.09
	<u>Raising funds</u>		
3,069.67	Family Support and Events	33,325.74	
5,778.53	Fundraising costs	3,695.97	
399.60	Just Giving	331.20	
<u>0.00</u>	Charity Checkout Online	<u>0.00</u>	
9,247.80			37,352.91
	<u>Other costs</u>		
928.60	Stationery, postage and telephone	1,019.87	
2,093.06	Computer, internet and website	2,968.12	
	Virtual Assistant	1,820.00	
0.00	Travel	0.00	
22.99	Training	739.93	
140.97	Trustees meetings	672.95	
155.29	Insurance	159.84	
0.00	Paypal charges and reader	0.00	
59.00	Bank charges	62.40	
1,981.29	Depreciation	639.45	
<u>360.00</u>	Independent examiner's fee	<u>360.00</u>	
5,741.20			8,442.56
59,480.48	Total payments		96,044.56
<u>(20,728.95)</u>	Surplus / (Deficit) for the year		<u>(25,147.33)</u>

FANCONI HOPE

STATEMENT OF ASSETS AND LIABILITIES

FOR THE YEAR ENDED 30 APRIL 2024

<u>2023</u>		<u>2024</u>
114,901.12	Accumulated reserves brought forward	94,124.53
(20,776.59)	Surplus / deficit for the year	(25,147.33)
<u>94,124.53</u>		<u>68,977.20</u>
Represented by:		
Fixed assets:		
500.00	Gazebo	500.00
6,880.53	IT equipment - grant funded	6,880.53
750.00	Projector - grant funded	750.00
799.99	Laptop	799.99
771.44	IT equipment - Videoconferencing	771.44
872.80	Laptop and SSD	872.80
179.00	Router	179.00
	Office chair	146.99
	Galaxy S7 tablet	479.00
(8,645.69)	Less depreciation (20% on cost)	(9,285.14)
<u>2,108.07</u>		<u>2,094.61</u>
3,344.34	Current Account	9,884.51
89,511.49	Business Premium Account	57,905.26
97.12	Paypal	270.48
(936.49)	(Creditor)/Debtor - Trustees expenses to be re-imbursed	(1,177.66)
<u>94,124.53</u>		<u>68,977.20</u>

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CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' Annual Report for the period

From 1 May 2023 To 30 April 2024

Charity name: FANCONI HOPE CHARITABLE TRUST

Charity registration number: 1126894

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	• To relieve the sickness of those children and adults suffering from Fanconi Anaemia • To promote awareness and advance the education of the medical profession and the public in all areas relating to Fanconi Anaemia • To promote research into the cause and treatment of Fanconi Anaemia for the public benefit
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	• Help in providing support and information for families affected by Fanconi Anaemia. Acting as a link to connect families in the UK and Ireland through events for affected families and through the use of email, our website and other social media. • Continued development of Long Term Effects of Fanconi Anaemia Study, 100% funded by the Charity. • 100% funding of Proton Beam Therapy research project at Manchester's Christie Hospital. • Partnering initiative set up with European Fanconi Anaemia support groups in an umbrella organisation called FA Europe. • Collaborations with US Fanconi Cancer Foundation
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	• The Trustees have had regard to the guidance issued by the Charity Commission on public benefit.

Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	Research Grants Our policy is to fund UK-based research projects.
Policy on social investment including program related investment	Para 1.38	
Contribution made by volunteers	Para 1.38	Volunteer Contributions. All Charity Trustees give their time voluntarily
Other		

Achievements and Performance

	SORP reference	
Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.	Para 1.20	Bringing Families Together: - Highly successful Family Conference weekend held in June 23, involving over 140 people from around the UK. Feedback on the benefits of the event to patients and parents was overwhelmingly positive. (Net Promoter Score was +89) Supporting Families - Our Collaborative National Lottery-funded Better Together Consortium Project has delivered significant support to patients and parents in relation to Emotional Wellbeing, Benefits and Travel Insurance Advice. Fundraising Activities - Families, friends and colleagues continue to contribute to the fundraising effort, actively supported by the Charity. Raising Awareness The Better Together Consortium Project has enabled greater awareness raising amongst families and healthcare professionals Promoting Research

		• The Fanconi Hope-funded Late Effects of Fanconi Anaemia Study is a long term Registry project which now holds data on more than 75 patients in the UK and over 1000 patient-years of data, allowing research on the data contained in the Registry to be undertaken and conclusions drawn. • Fanconi Hope is funding a research project into the use of Proton Beam Therapy for treatment of cancers in patients with FA. Programme is now in year 3 with a 4th year extension planned. Initial results from the work are proving very informative to the medical community. • Fanconi Hope continues to play its part in the Fanconi Anemia Global Network set up in the US to discuss development of greater family support and research networks across the world. • We continue with the development of the FA Europe network, which we helped to initiate in 2019, to help with common approaches to research and patient support amongst a scarce set of European medical experts. Our first Europe-wide Scientific Meeting is planned for May 24.
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Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	
Performance of fundraising activities against objectives set	Para 1.41	
Investment performance against objectives	Para 1.41	
Other		All monies raised are held within standard and high interest bank accounts with HSBC

Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	Income:£ 70897 Expenditure: £ 96044 Deficit (£ 25147) Statement of Assets and Liabilities: Accum reserves brought forward: £94125 Surplus for year: (£25147) Total £68977 Consisting of:- Fixed assets less depreciation: £2095 • Current Account: £9885 • Business Premium Account: £57905 • Paypal: £270 • Trustees expenses to be reimbursed:(£ 1178)
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	Reserves policy is to maintain a balance of at least £20,000 to cover normal operating expenses and provide an acceptable level of family support. Research projects will only be initiated when the full amount of the project is held in the bank in addition to the reserves held.
Amount of reserves held	Para 1.22	£20,000
Reasons for holding zero reserves	Para 1.22	N/A
Details of fund materially in deficit	Para 1.24	N/A
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	No uncertainties or concerns

Additional information (optional)

You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	Fundraising events organised by families and friends and through direct donations from companies and private individuals remain the main source of funds for the Charity.
Investment policy and objectives including any social investment policy adopted	Para 1.46	
A description of the principal risks facing the charity	Para 1.46	
Other		

Structure, Governance and Management

Description of charity's trusts:		Single Trust, inaugurated 4 th May 2008
Type of governing document	Para 1.25	Trust Deed

(trust deed, royal charter)		
How is the charity constituted? (e.g unincorporated association, CIO)	Para 1.25	Unincorporated association
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	Selection and election by existing board of Trustees

Additional information (optional)

You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	
The charity's organisational structure and any wider network with which the charity works	Para 1.51	
Relationship with any related parties	Para 1.51	Fanconi Hope is a member of the following organisations: • Genetic Alliance UK • Specialised Healthcare Alliance • Together for Healthy Marrow Alliance • National Council of Voluntary Organisations • Institute of Fundraising Fanconi Hope also works closely with sister organisations outside the UK involved with Fanconi Anaemia family support, principally the Fanconi Cancer Foundation in the US and the FA Europe network
Other		

Reference and Administrative details

Charity name	Fanconi Hope Charitable Trust
Other name the charity uses	
Registered charity number	1126894

Charity's principal address	New Street Centre, New Street, Chesterfield, S40 2JZ

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Mr Robert Dalgleish	Chairman		Board of Trustees
2	Dr Nigel J Jones	Treasurer		Board of Trustees
3	Mrs Beth Lee	Secretary		Board of Trustees
4	Prof Josu de la Fuente	Board member		Board of Trustees
5	Dr Stefan Meyer	Board member		Board of Trustees
6	Prof Marc Tischkowitz	Board member		Board of Trustees
7	Dr Roshni George	Board member		Board of Trustees
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Corporate trustees – names of the directors at the date the report was approved

Director name		

Name of trustees holding title to property belonging to the charity

Trustee name	Dates acted if not for whole year	
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Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	None
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	N/A
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	N/A

Additional information (optional)

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

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Exemptions from disclosure

Reason for non-disclosure of key personnel details

N/A

Other optional information

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Declarations

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Robert Alexander Dalglish	
Position (eg Secretary, Chair, etc)	Chair	

Date

20 th February 2025
