

FANCONI HOPE

Independent Examiner's Report to the Trustees of

Fanconi Hope

For the year ended 30 April 2022

I report on the accounts of the charity for the year ended 30 April 2022, 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.



Rachel Hall  
R S Hall and Co  
27 Belle Meade Close  
Woodgate  
Chichester  
West Sussex  
PO20 3YD

Date: 26 February 2023



**FANCONI HOPE**

**STATEMENT OF ACCOUNTS**

**FOR THE YEAR ENDED 30 APRIL 2022**



**FANCONI HOPE**

**INCOME AND EXPENDITURE ACCOUNT**

**FOR THE YEAR ENDED 30 APRIL 2022**

<u>2021</u>		<u>2022</u>	
	<b><u>RECEIPTS</u></b>		
26,154.11	Donations	34,031.47	
0.00	Grant	2,500.00	
846.26	Gift Aid	298.44	
64.80	Bank interest	13.11	
<u>27,065.17</u>		<u>36,843.02</u>	
	<b><u>PAYMENTS</u></b>		
	<u>Charitable Activities</u>		
0.00	FA Europe	0.00	
0.00	Conference costs	0.00	
15,257.00	Research costs	38,142.50	
300.00	Subscriptions	250.00	
<u>15,557.00</u>		<u>38,392.50</u>	
	<u>Raising funds</u>		
0.00	Family Support	0.00	
479.99	Fundraising costs	5,050.99	
331.20	Just Giving	0.00	
0.00	Charity Checkout Online	0.00	
<u>811.19</u>		<u>5,050.99</u>	
	<u>Other costs</u>		
516.48	Stationery, postage and telephone	1,083.88	
1,195.57	Computer, internet and website	1,012.28	
0.00	Travel	0.00	
5.00	Training	0.00	
0.00	Trustees meetings	0.00	
151.78	Insurance	153.51	
42.91	Paypal charges and reader	96.76	
0.00	Bank charges	35.25	
1,626.10	Depreciation	1,786.10	
300.00	Independent examiner's fee	360.00	
<u>3,837.84</u>		<u>4,527.78</u>	
20,206.03	Total payments	47,971.27	
<u>6,859.14</u>	Surplus / (Deficit) for the year	<u>(11,128.25)</u>	



**FANCONI HOPE**

**STATEMENT OF ASSETS AND LIABILITIES**

**FOR THE YEAR ENDED 30 APRIL 2022**

<u>2021</u>		<u>2022</u>
119,170.23	Accumulated reserves brought forward	126,029.37
6,859.14	Surplus / deficit for the year	(11,128.25)
<u>126,029.37</u>		<u>114,901.12</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
0.00	Laptop	799.99
<u>(4,878.30)</u>	Less depreciation (20% on cost)	<u>(6,664.40)</u>
3,252.23		2,266.12
3,185.79	Current Account	8,296.89
120,116.58	Business Premium Account	104,129.69
558.14	Paypal	1,105.05
(1,083.37)	(Creditor)/Debtor - Trustees expenses to be re-imbursed	(936.49)
0.00	Mischarged expenses - reimbursed 19/02/2023	39.86
<u>126,029.37</u>		<u>114,901.12</u>



DONATIONS	FUNDRAISING PAYPAL	GRANTS
-----------	--------------------	--------

20.00		
47.92		
72.76		
	500.00	
14.02		
27.52		
41.75		
4.75		
20.00		
28.50		
356.06		
1,855.00		
105.67		
271.87		
4.75		
80.90		
20.00		
300.00		
130.19		
232.19		
77.35		
4.75		
30.00		
20.00		
156.56		
36.35		
136.98		
63.95		
20.00		
116.72		
79.53		
4.75		
11.87		
367.84		
20.00		
1,202.91		
731.67		
134.10		



96.10		
836.53		
334.34		
4.75		
57.32		
179.26		
20.00		
97.30		
150.00		
25.63		
96.10		
114.81		
25.00		
20.00		
45.76		
7.12		
	48.00	
	2,173.20	
66.00		
18.00		
1.90		
615.00		
96.10		
90.63		
5.94		
4.75		
7.12		
28.50		
20.00		
32.58		
1.90		
4.45		
200.00		
65.18		2500
4.75		
51.55		
20.00		
14.24		
261.74		
1.90		
22.62		
2,104.48		
141.30		
4.75		
382.22		
20.00		
331.24		
500.00		



996.80  
30.00  
142.46  
1,253.28  
118.25  
20.90  
50.17  
28.20  
214.82  
37.59  
64.10  
4.75  
2,554.44  
148.68  
5,090.90  
876.53  
25.00  
1,439.99  
918.08  
95.80  
797.12  
200.16  
242.58  
50.00  
25.00  
4.75  
414.10  
110.41  
77.67  
173.93  
30.85  
293.03  
18.52  
86.55  
4.75

52,237.84

30,718.20	2,721.20	0.00	2,500.00
-----------	----------	------	----------



BANK RECONCILIATION

CURRENT ACCOUNT

Opening balance	3,185.79
Add receipts	52,237.84
Less payments	-47,126.74
	<u>8,296.89</u>

Balance per statement	8,296.89
Less o/s payments	
	<u>8,296.89</u>

DEPOSIT ACCOUNT

Opening balance	120,116.58
Add receipts	
Interest	13.11
Donations	
Transfers	
Transfer to current account	-16,000.00
	<u>104,129.69</u>

Balance per statement	120,116.58
Less o/s payments	
	<u>120,116.58</u>



	47126.74	0.00
	96.76	
	47223.5	

accounts	46185.17
bal sheet	839.85
bob	176.87
	47201.89



TRANSFER	DONATIONS	FUNDRAISING SUPPORT	FAMILY SUPPORT	digital trust	TRANSFERS	ONLINE GIVING	CHARGES
	100					6.25	1.6
	8.84					1.25	0.48
	20					21.5	5.01
	0.32					0.05	0.21
	1					0.05	0.21
	1					0.06	0.21
	343.91					3.13	0.9
	1					1.88	0.62
	1					0.06	0.21
	1					1	0.48
	1						
	50						
	30				51.6		
51.6							
	1						
	20						
	1.25						
	10.75						
<b>643.67</b>	51.60	592.07					
		<b>96.76</b>	0.00	0.00	51.60	0.00	35.23
							9.93

Opening balance	558.14
Add receipts	643.67
Less payments	(96.76)
	<u>1,105.05</u>
	887.83





**CHARITY COMMISSION**  
FOR ENGLAND AND WALES

## Trustees' Annual Report for the period

From 1 May 2021 To 30 April 2022

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	<ul style="list-style-type: none"><li>• To relieve the sickness of those children and adults suffering from Fanconi Anaemia</li><li>• To promote awareness and advance the education of the medical profession and the public in all areas relating to Fanconi Anaemia</li><li>• To promote research into the cause and treatment of Fanconi Anaemia for the public benefit</li></ul>
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	<ul style="list-style-type: none"><li>• 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.</li><li>• Continued development of Long Term Effects of Fanconi Anaemia Study, 100% funded by the Charity.</li><li>• 100% funding of Proton Beam Therapy research project at Manchester's Christie Hospital.</li><li>• Partnering initiative set up with European Fanconi Anaemia support groups in an umbrella organisation called FA Europe.</li></ul>
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	<ul style="list-style-type: none"><li>• The Trustees have had regard to the guidance issued by the Charity Commission on public benefit.</li></ul>



--	--	--

### 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	<p>Bringing Families Together: Due to COVID, a planned Conference weekend had to be postponed yet again. A social weekend, in conjunction with our Dutch counterpart organisation, is however being scheduled for the summer of 2022 for adults with Fanconi Anaemia.</p> <p>Fundraising Activities:</p> <ul style="list-style-type: none"> <li>Families, friends and colleagues continue to contribute to the fundraising effort, actively supported by the Charity. An unrestricted grant of £2500 was received from the Jeans for Genes organisation.</li> <li>We have applied for a very significant National Lottery Grant in collaboration with 6 other small charities called the Together for Healthy Marrow Alliance and are very confident of success.</li> </ul>



		<p>Raising Awareness</p> <ul style="list-style-type: none"> <li>The use of social media continues to prove effective in reaching out to a much wider audience than just the relatively small number of families affected by Fanconi Anaemia.</li> </ul> <p>Promoting Research</p> <ul style="list-style-type: none"> <li>The Fanconi Hope-funded Long Term Effects of Fanconi Anaemia Study is a long term Registry project which now holds data on more than 60% of the known patients in the UK.</li> <li>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 1 of a 3 year PhD programme of work.</li> <li>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.</li> <li>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</li> </ul>
--	--	--

#### Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	<p>Regular briefings provided for our community, who have been severely affected by COVID-19 due to restricted access to medical care and the attendant risks of immunosuppression affecting many of them.</p> <p>Greater reach and access to expertise achieved through both UK and worldwide collaborations.</p>
Performance of fundraising activities against objectives set	Para 1.41	<p>Our ambitious target of £100K to fund a Proton Therapy Research Project was achieved in 20/21, as predicted, and the project is now under way.</p>
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:£ 36843.02 Expenditure: £ 47971.27 Surplus (£ 11128.25) Statement of Assets and Liabilities: Accum reserves brought forward: £126029.37 Surplus for year: (£ 11128.25) Total £114901.12 Consisting of:- Fixed assets less depreciation: £2266.12 <ul style="list-style-type: none"> <li>• Current Account: £8296.89</li> <li>• Business Premium Account: £104129.69</li> <li>• Paypal: £1105.05</li> <li>• Trustees expenses to be reimbursed:(£ -896.63)</li> </ul>
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 <sup>th</sup> May 2008
Type of governing document ( <a href="#">trust deed</a> , <a href="#">royal charter</a> )	Para 1.25	Trust Deed
How is the charity constituted? (e.g <a href="#">unincorporated association</a> , 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	<p>Fanconi Hope is a member of the following organisations:</p> <ul style="list-style-type: none"> <li>• Genetic Alliance UK</li> <li>• Gene People</li> <li>• Specialised Healthcare Alliance</li> <li>• Together for Healthy Marrow Alliance</li> <li>• National Council of Voluntary Organisations</li> <li>• Institute of Fundraising</li> </ul> <p>Fanconi Hope also works closely with sister organisations outside the UK involved with Fanconi Anaemia family support, principally the Fanconi Anemia Research Fund in the US and the FA Europe network</p>
Other		



## Reference and Administrative details

Charity name	Fanconi Hope Charitable Trust
Other name the charity uses	
Registered charity number	1126894
Charity's principal address	16 Andover Road, Southsea, PO4 9QG. Also via forwarding to same address via PO Box 905 Southsea PO1 9JG

## 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 Dalglish	Chairman		Board of Trustees
2	Mrs Louise Parry	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 Nigel J Jones	Board member		Board of Trustees
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

## 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	

## 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)

--

## Exemptions from disclosure

Reason for non-disclosure of key personnel details

N/A
-----

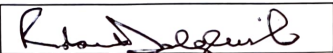


Other optional information

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	

Date26<sup>th</sup> February 2023