

FANCONI HOPE

Independent Examiner's Report to the Trustees of

Fanconi Hope

For the year ended 30 April 2020

I report on the accounts of the charity for the year ended 30 April 2020, 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: 3 February 2021

**FANCONI HOPE**

**STATEMENT OF ACCOUNTS**

**FOR THE YEAR ENDED 30 APRIL 2020**

**FANCONI HOPE**

**INCOME AND EXPENDITURE ACCOUNT**

**FOR THE YEAR ENDED 30 APRIL 2020**

<u>2019</u>		<u>2020</u>	
	<b><u>RECEIPTS</u></b>		
84,183.16	Donations	51,579.88	
7,587.30	Grant	5,000.00	
6.15	Bank interest	155.07	
<u>91,776.61</u>			56,734.95
	<b><u>PAYMENTS</u></b>		
	<u>Charitable Activities</u>		
0.00	FA Europe	818.08	
4,396.01	Conference costs	837.68	
200.00	Subscriptions	150.00	
<u>4,596.01</u>			1,805.76
	<u>Raising funds</u>		
153.98	Family Support	18,301.28	
5,514.80	Fundraising costs	4,499.80	
561.60	Just Giving	561.60	
359.99	Charity Checkout Online	479.99	
<u>6,590.37</u>			23,842.67
	<u>Other costs</u>		
651.94	Stationery, postage and telephone	691.90	
280.65	Computer, internet and website	864.33	
972.29	Travel	1,098.73	
122.80	Training	88.12	
281.30	Trustees meetings	147.00	
168.03	Insurance	170.23	
12.29	Paypal charges and reader	42.04	
0.00	Bank charges	10.80	
1,626.10	Depreciation	1,626.10	
300.00	Independent examiner's fee	360.00	
<u>4,415.40</u>			5,099.25
15,601.78	Total payments		30,747.68
<u><u>76,174.83</u></u>	Surplus / (Deficit) for the year	<u><u>25,987.27</u></u>	

**FANCONI HOPE**

**STATEMENT OF ASSETS AND LIABILITIES**

**FOR THE YEAR ENDED 30 APRIL 2020**

<u>2019</u>		<u>2020</u>
17,008.13	Accumulated reserves brought forward	93,182.96
76,174.83	Surplus / deficit for the year	25,987.27
<u>93,182.96</u>		<u>119,170.23</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
(1,626.10)	Less depreciation (20% on cost)	(3,252.20)
6,504.43		4,878.33
40,817.10	Current Account	6,651.51
46,627.03	Business Premium Account	110,051.78
140.93	Paypal	887.83
(906.53)	(Creditor)/Debtor - Trustees expenses to be re-imbursed	(3,239.22)
0.00	Accrual independent examiner	(60.00)
<u>93,182.96</u>		<u>119,170.23</u>



**CHARITY COMMISSION**  
FOR ENGLAND AND WALES

## **Trustees' Annual Report for the period**

**From 1 May 2019 To 30 April 2020**

**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 Northern 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>• Major fundraising drive for research into Proton Beam Therapy at Manchester 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>

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### 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: A highly successful Family Conference and Social Weekend was held in Sept 19, with talks from Fanconi anaemia specialists and plenty of time for families to get to know each other and share experiences.</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. The level of donations this year has continued at a high level, with a fundraising drive for Proton Therapy Research going well.</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. The recent use of Instagram has proved</li> </ul>

		<p>an effective way of communicating with the younger community.</p> <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 50% of the known patients in the UK.</li> <li>• Fundraising efforts have been directed at research into the use of Proton Beam Therapy for treatment of cancers in patients with FA.</li> <li>• Fanconi Hope is now part of a Fanconi Anemia Global Network set up to discuss development of greater family support and research networks across the world.</li> <li>• In conjunction with our involvement in the European FA Umbrella group, we now have access to key clinicians and researchers around the world.</li> </ul>
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#### **Additional information (optional)**

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	Organised a Family Conference and Social Weekend. Feedback showed this was very highly valued. Greater reach and access to expertise achieved through worldwide collaborations.
Performance of fundraising activities against objectives set	Para 1.41	Ambitious target of £100K set to fund Proton Therapy Research Project. Fundraising to date shows this to be an achievable target in 2020/21.
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	<p>Income:£56,735  Expenditure: £30,748  Surplus £25,987  Statement of Assets and Liabilities:  Accum reserves brought forward: £93,183  Surplus for year: £25,987  Total £119,170.  Consisting of:-  Fixed assets less depreciation: £4,878</p> <ul style="list-style-type: none"> <li>• Current Account: £6,652</li> <li>• Business Premium Account: £110,052</li> <li>• Paypal: £888</li> <li>• Trustees expenses to be reimbursed:(£3,239)</li> <li>• Accrual independent examiner (£60)</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 (trust deed, royal charter)	Para 1.25	Trust Deed
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	<p>Fanconi Hope is a member of the following organisations:</p> <ul style="list-style-type: none"> <li>• Genetic Alliance UK</li> <li>• Genetic Disorders UK</li> <li>• Small Charities Coalition</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</p>
Other		

#### **Reference and Administrative details**



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)

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## Exemptions from disclosure

Reason for non-disclosure of key personnel details


N/A
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## 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 Dalgleish	
Position (eg Secretary, Chair, etc)	Chair	

Date

18<sup>th</sup> February 2021