



CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' Annual Report for the period

From 1 May 2018 To 30 April 2019

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">• 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	<ul style="list-style-type: none">• 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.• Consolidation of Long Term Effects of Fanconi Anaemia Study into a truly long term study, 100% funded by the Charity.• Major fundraising drive for research into Proton Beam Therapy at Manchester Christie Hospital.
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">• 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	
		Research Grants

Policy on grant making	Para 1.38	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:</p> <ul style="list-style-type: none"> The website (www.fanconihope.org) has been rebuilt and is now secure and mobile-friendly. Our Facebook site (www.facebook.com/fanconihope) and Twitter (@fanconihope) have become increasingly popular as a focus for all activities and to provide the means for sharing information. Through the efforts of our Fanconi Hope-funded Research Project Liaison Officer, Beth Lee, increasing numbers of families are now in contact, both contributing to the Long Term Effects of FA Registry and receiving guidance from Beth, an experienced FA nurse. <p>Fundraising Activities:</p> <ul style="list-style-type: none"> Families, friends and colleagues continue to contribute to the fundraising effort, actively supported by the Charity. The level of donations this year has been significantly higher than in any previous year The Charity applied for and secured an £7500 grant from the National Lottery Big Lottery fund to provide much needed IT equipment for Charity members and for conference events.

		<p>Raising Awareness</p> <ul style="list-style-type: none"> 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. <p>Promoting Research</p> <ul style="list-style-type: none"> Consolidation of the Fanconi Hope-funded Long Term Effects of Fanconi Anaemia Study into a truly long term Registry project, (to 2024). Initial discussions held with the US Fanconi Anemia Research Fund (FARF) with a view to potential FARF grant funding on a study into the use of Proton Beam Therapy for treatment of cancers in patients with FA. Attendance at the inaugural Fanconi Anemia Global Network Summit Meeting in California to discuss development of greater family support and research networks across the world.
--	--	---

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	The funds raised over the years have allowed the charity to organise family days, sponsor/attend medical conferences, sponsor world class UK-based gene therapy research, initiate an International Gene Therapy Working Group, and raise better awareness amongst clinicians and the general public.
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:£91777 Expenditure: £15,602 Surplus £76,175 Statement of Assets and Liabilities: Accum reserves brought forward: £17,008 Surplus for year: £76,175 Total £93,183. Consisting of:- Fixed assets less depreciation: £6,504</p> <ul style="list-style-type: none"> • Current Account: £40,817 • Business Premium Account: £46,627 • Paypal: £141 • Trustees expenses to be reimbursed:£907
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	<p>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.</p> <p>This year, however, we secured an £7500 grant from the National Lottery Big Lottery fund to provide much needed IT equipment for Charity members and for conference events</p>
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 (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"> • Genetic Alliance UK • Genetic Disorders UK • Small Charities Coalition • Specialised Healthcare Alliance • Together for Healthy Marrow Alliance • National Council of Voluntary Organisations • Institute of Fundraising <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

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	(from 19.6.19)	Board of Trustees
4	Dr Josu de la Fuente	Board member		Board of Trustees
5	Dr Stefan Meyer	Board member		Board of Trustees
6	Dr 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	

Date	14 th February 2020
------	--------------------------------

FANCONI HOPE

STATEMENT OF ACCOUNTS

FOR THE YEAR ENDED 30 APRIL 2019

FANCONI HOPE

INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 30 APRIL 2019

2018

RECEIPTS

10,002.51	Donations	84,183.16	
0.00	Grant	7,587.30	
1.70	Bank interest	6.15	
<u>10,004.21</u>			91,776.61

PAYMENTS

Charitable Activities

31,905.67	Research Funding	0.00	
6,522.87	Conference costs	4,396.01	
125.00	Subscriptions	200.00	
<u>38,553.54</u>			4,596.01

Raising funds

394.80	Family Support	153.98	
0.00	Fundraising costs	3,239.01	
446.40	Just Giving	561.60	
0.00	Charity Checkout Online	359.99	
127.26	T shirts and wrist bands	1,822.49	
591.00	Collection boxes and banners	453.30	
<u>1,559.46</u>			6,590.37

Other costs

524.31	Stationery, postage and telephone	651.94	
115.05	Computer, internet and website	280.65	
209.15	Travel	972.29	
135.00	Training	122.80	
0.00	Trustees meetings	281.30	
193.00	Insurance	168.03	
76.98	Paypal charges and reader	12.29	
30.00	Bank charges	0.00	
0.00	Depreciation	1,626.10	
300.00	Independent examiner's fee	300.00	
<u>1,583.49</u>			4,415.40

41,696.49	Total payments	15,601.78
-----------	----------------	-----------

<u>(31,692.28)</u>	Surplus / (Deficit) for the year	<u>76,174.83</u>
--------------------	----------------------------------	------------------

FANCONI HOPE

STATEMENT OF ASSETS AND LIABILITIES

FOR THE YEAR ENDED 30 APRIL 2019

<u>2018</u>		<u>2019</u>
48,700.41	Accumulated reserves brought forward	17,008.13
(31,692.28)	Surplus / deficit for the year	76,174.83
<u>17,008.13</u>		<u>93,182.96</u>
Represented by:		
Fixed assets:		
500.00	Gazebo	500.00
0.00	IT equipment - grant funded	6,880.53
0.00	Projector - grant funded	750.00
0.00	Less depreciation (20% on cost)	<u>(1,626.10)</u>
500.00		6,504.43
13,266.16	Current Account	40,817.10
3,751.27	Business Premium Account	46,627.03
92.52	Paypal	140.93
(601.82)	(Creditor)/Debtor - Trustees expenses to be re-imbursed	(906.53)
<u>17,008.13</u>		<u>93,182.96</u>

BANK RECONCILIATION

CURRENT ACCOUNT

Opening balance	13,266.16	
Add receipts	89,840.15	
Less payments	-62,289.21	0.00
	<u>40,817.10</u>	

Balance per statement	40,817.10
Less o/s payments	
	<u>40,817.10</u>

DEPOSIT ACCOUNT

Opening balance	3,751.27
Add receipts	
Interest	6.15
Donations	1,869.61
Transfers	41,000.00
	<u>46,627.03</u>

Balance per statement	46,627.03
Less o/s payments	
	<u>46,627.03</u>

TRANSFER DONATIONS			FUNDRAISING SUPPORT TRANSFERS		ONLINE GIVING	CHARGES	
					128.12	0.21	
1,498.54	1.01		1,498.54			0.49	
	21.00					0.34	
	10.00					0.48	
196.69	20.00		196.69		1.25	0.35	
	0.55					0.94	
	10.63				0.66	0.34	
	53.13				3.32	0.94	
	10.00					0.34	
	52.50				2.63		
	10.00						
1,884.05	1,695.23	188.82	1,835.64	1,695.23	128.12	7.86	4.43

Opening balance	92.52
Add receipts	1,884.05
Less payments	(1,835.64)
	<u>140.93</u>

FANCONI HOPE

Independent Examiner's Report to the Trustees of

Fanconi Hope

For the year ended 30 April 2019

I report on the accounts of the charity for the year ended 30 April 2019, 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: 16 February 2020