

Annual Report of Trustees 2020-2021

Introduction to The George Pantziarka TP53 Trust

The George Pantziarka TP53 Trust is a small charity that supports individuals and families with Li Fraumeni Syndrome (LFS) and related TP53 disorders.

Individuals with LFS are born with a damaged TP53 gene – the body's key anti-cancer gene. Consequently, the risk of developing a first cancer is 90% - 100%, with a 50% chance of developing a second. Whole families can be affected and childhood cancers are common. A diagnosis of LFS in a child is particularly devastating, but it can be a lonely and frightening existence for anyone suffering from LFS. The Trust was established because there are no other support groups, charities or central information resources in the UK, and it is a rare condition that is not a prime focus for research or fundraising. Leading clinicians estimate that the total number of individuals with LFS in the UK is between 3,200 and 12,800, but there are currently only between 400 and 500 people diagnosed.

The trustees of the George Pantziarka TP53 Trust are elected by other trustees. We currently have 5 trustees –

Pan Pantziarka, Chair
Irene Pantziarka, Vice-Chair
Natasha Bramble, Treasurer
Gillian Winskill, Secretary
Elizabeth Sam

The trust has no permanent staff and is run by trustees and helped at specific events by a small group of volunteers. In carrying out our duties as trustees and in organising public events we are aware of the need to guard against certain risks. Consequently, we have created, and pay due regard to, our risk management register, our policies in relation to volunteer management, conflict of interest, payment to trustees and our vulnerable beneficiaries policy. This year we added a complaints policy.

What are our objects?

The objects of The George Pantziarka TP53 Trust are to provide financial assistance, support, education and practical advice for people with LFS and related disorders in the UK; to advance education of the general public and of the medical profession in particular, in all areas; to promote and publish research.

What have we done to fulfil our objects?

In order to carry out our objects, we have undertaken certain activities during our financial year 2020 - 2021. In so doing, we have paid due regard to our objects and the public benefit guidance issued by the Charity Commission of England and Wales – in PB1, PB2 and PB3 (published Sept 2013).

This year, we have contributed to several projects aimed at improving the life of people with LFS and their families. These include: -

- Continuing to work with the University of Oxford to develop a clinical trial of the antidiabetic drug metformin as a treatment for people with LFS. The Metformin in Li Fraumeni Syndrome (MILI) trial aims to reduce their risk of cancer. In addition to working on the grant application to the National Institute of Health Research, we have canvassed LFS patients on aspects of the trial design, written plain English summaries of the project, and incorporated a patient and public involvement (PPI) plan for the trial
- Continuing our involvement in the steering committee for the development of a national LFS register. In addition to working with academic and clinical groups, we have also consulted with software development professionals to further gain understanding of the technical infrastructure for the type of system envisaged.
- We have developed new links with research groups working in LFS and TP53. These links are essential to access new research on drugs which may one day be useful as treatments for people with LFS.
- Collaborating with *Living LFS* – our equivalent in the US - by promoting LFS Awareness Day here in the UK through social media, with #WearBlueForLFS. Along with some of our supporters with LFS, we also took part in discussions online and maintained a very visible internet presence during this event.

What else?

Although we planned for our annual national conference in June 2020, we were forced to cancel as a result of Covid 19.

We have continued to maintain the trust's social media presence through Facebook, our website and our Instagram page. We have continued to publish new material on our website, and we continue to respond to individuals who require advice and support. We have maintained our efforts to develop our contacts with genetic testing centres in the UK.

What have we achieved?

With our involvement in the screening guidelines group, the MILI trial, the national register and the screening protocol we have continued to establish the trust as a knowledgeable voice that is able to advocate for LFS patients. We are thus able to have more impact on the development of research and the meeting of patient needs and demands.

Families with members who have LFS are becoming more aware of our existence, as we reach out to more people through social media and through our clinician contacts in genetic testing centres.

Funding and Finance

The trust has had no formal reserve policy or separate reserve account, as we have been dealing with an annual income of under £20k. However, this has increased during the year 2020-2021, and the trustees plan to watch and review this in the coming year. Meanwhile, it is the trustees' decision to ensure the current account does not fall below five thousand pounds, which would still enable us to continue our basic activities.

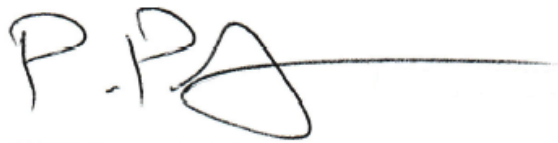
Our principal source of funding has always been from individual donations and small fundraising events such as fun runs and school charity events. However, early in 2021 we received a large donation from Stafford Capital. We also became one of the supported charities of Bamboo Loans, who have developed a relationship with us that extends beyond the provision of funding/donations and has included pro bono design work for our website and printed materials.

Declaration of Trustees

I certify that this report has been read and approved by trustees.

Signed on behalf of trustees:

(Pan Pantziarka, Chair)

A handwritten signature in black ink, appearing to be 'P. Pantziarka', followed by a long horizontal line extending to the right.

Date: 19/01/22



The George Pantziarka TP53 Trust	Charity No 1157167
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Receipts and Payments Accounts

For the period from	Period start date 01/04/2020	To	Period end date 31/03/2021
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Section A Receipts and Payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
My Donate	-	-	-	-	179
CTT Charity Payments/Everyclick	115	-	-	115	106
Farmers' Market	-	-	-	-	466
Virginmoney Giving	3,095	-	-	3,095	3,247
Amazon Europe Core	49	-	-	49	12
Stafford Capital	29,450	-	-	29,450	-
Bamboo Ltd	2,000	-	-	2,000	-
	-	-	-	-	-
Miscellaneous	425	-	-	425	90
Sub total (Gross income for AR)	35,134	-	-	35,134	4,100
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	35,134	-	-	35,134	4,100
A3 Payments					
Hiscox Insurance	103	-	-	103	97
Abricot Design - Website Hosting	90	-	-	90	90
Genetic Alliance membership	-	-	-	-	50
Printed bags and Flags	-	-	-	-	569
Annual Conference	-	-	-	-	2,119
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Miscellaneous	-	-	-	-	13
Sub total	193	-	-	193	2,912
A4 Asset and investment purchases,					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	193	-	-	193	2,912
Net of receipts/(payments)	34,941	-	-	34,941	1,188
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	19,560	-	-	19,560	18,372
Cash funds this year end	54,501	-	-	54,501	19,560

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	HSBC Account	54,501	-	-
		-	-	-
		-	-	-
	Total cash funds	54,501	-	-
	(agree balances with receipts and payments account(s))			
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities			-	
			-	
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees		Signature	Print Name	Date of approval
	P.P.A.	P Pantziarka (Chair)	14/12/2021	
	Natasha Bramble	N Bramble (Treasurer)	14/12/21	

Independent Examiner's Report

To the members of the George Panziarka TP53 Trust

For the year ending 31st March 2021

BASIS OF INDEPENDENT EXAMINER'S REPORT

My examination was carried out in accordance with the general Directions given by the Charities Commission. This examination includes a review of the accounting records held by the Trust showing receipts of £35,134 and payments of £193 in the year to 31-3-21 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 Trust 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 below.

INDEPENDENT EXAMINER'S STATEMENT

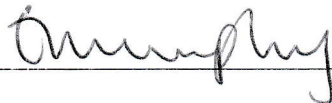
In connection with my examination, no matter has come to my attention:

- 1 which gives me reasonable cause to believe that in any material respect the requirements to keep accounting records and to prepare accounts which accord with the accounting records 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.

Signed



Dated

4-1-22

Emma Murphy
24 Cumberland Drive
Esher
Surrey
KT10 0BB