REPORT OF THE TRUSTEES AND

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UNAUDITED FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MAY 2019

FOR

THE BUTTERFLY AVM CHARITY LIMITED (A COMPANY LIMITED BY GUARANTEE)

> G. George Associates 12 Gateway Mews Ring Way London N11 2UT

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REPORT OF THE TRUSTEES For The Year Ended 31 MAY 2019

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 May 2019. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015).

OBJECTIVES AND ACTIVITIES

Objectives and aims

The charity's primary objective is to raise funds for specific research into peripheral, brain and extremity Arteriovenous Malformations (AVMs). The policies adopted in furtherance of these objects are to raise money through events and promotions and donate the proceeds to institutions that conduct research into improving treatments for AVMs and finding a cure. There has been no change in these during the year.

The charity aims to both improve existing treatments for AVMs and highlight new potential treatments that can benefit AVM sufferers. The charity is also committed to finding a cure, and to establish a comprehensive database of Doctors, Surgeons, Radiologists and Treatment Centres.

The charity's objectives for the year are to continue specifically funding AVM research in the form of providing funding for a PHD student with a remaining 2 year grant at the UCL in conjunction with Great Ormond Street Hospital and to go into phase 3 by studying the results and find more genetic mutations that are the cause of AVM and to target them with initial drug therapy and/or to utilise base editing.

The Charity have also reached an agreement in 2020 with The Royal Free London Hospital and UCL to fund an AVM Research and scientific programme comprising of £48,580 for a Post-doctorate research assistant for 1 year and to fund £87,500 for a PhD studentship (for 3.5 years) paid yearly

1st Year £25,000 2nd Year £25,000 3rd Year £25,000 4th Year £12,500

Total Funding agreed £136,080

Nikki has continued with her tremendous charity work and raising AVM awareness with her frequent appearance on various media sources. Her CBBC Program "My Life Born to Vlog" in which she talks about her life was nominated for a BAFTA and an Emmy. Nikki also continues her work with The Changing Faces Charity as an Ambassador to Champion positive representation of being different.

On 14th November 2019: The British Academy of Film and Television Arts (BAFTA) announced that Nikki Lilly will become the youngest ever recipient of a BAFTA Special Award at the 2019 British Academy Children's Awards for her inspiration to others and charity campaigning.

Nikki is now in her Third Series "Nikki Lilly Meets" on CBBC and despite her condition inspires people around the world daily with her never ending zest for life. We hope her story will in turn lead to more publicity for our charity so that more volunteers can help us raise our profile even further and increase our funding raised.

Our charity is going from strength to strength. We are a small charity that dreams big and hope that one day all our efforts will come to fruition and a cure for this debilitating illness will be found.

REPORT OF THE TRUSTEES For The Year Ended 31 MAY 2019

OBJECTIVES AND ACTIVITIES

Significant activities

The charity continues to fund vital AVM research at Great Ormond Street and the UCL. The research that we have solely funded has had amazing results.

The charity continues to fund vital research at Great Ormond Street and the UCL. We are proud that our charity have recently agreed a further 3.5 years AVM funding for researchers to carry on the Genetic investigation and therapy for arteriovenous malformations and specifically to allow for a PHD student to specifically research into AVMs and thus maximize our breakthroughs in this field as historically rare diseases have lacked funding to complete projects and utilize results for better treatments and advancements in the genetic structure of AVMs in order to find targeted drug treatments. The cost of this grant has been described in the "Objectives and Activities" section of this report.

An extract from Dr Kinsler The Head of Research Outline scientific proposal, AVM Butterfly PhD studentship

Veronica Kinsler, July 2018

Title: Genetic investigation and therapy for arteriovenous malformations

"We have recently discovered the genetic basis of AVMs in a third of cases. These are post-zygotic mutations in oncogenes MAP2K1, KRAS and BRAF. As part of this project we established human endothelial cell lines transfected with mutant constructs for functional characterization of the disease. We also published data from a novel zebrafish model demonstrating that repurposing of cancer therapies BRAF and MEK inhibition improves the clinical phenotype.

We now propose to:

1) continue to investigate the genetic basis of the other two thirds of cases using fresh biopsies, and deep DNA and RNA sequencing;

2) use the established the transgenic human endothelial cell lines to run FDA approved drug screens, plus KRAS inhibitors which are in development and lab use, plus siRNA (initially) and shRNA (ultimately if successful), and in combination with the best drug candidates, to rescue clinical and molecular phenotype;

3) if no clear benefit from point 2, to utilize base editing (where appropriate mutation), or CRISPR/Cas9 to correct the heterozygous missense mutations;

4) establish primary endothelial cell cultures for the eventual testing of the best candidates from point 2 and 3.

Nikki's drug treatment with ethanol in the US and its efficacy has paved the way in establishing a partnership and a sharing of knowledge with hospitals such as The Royal Free Hospital who now use Ethanol as part of their AVM treatment and have frequent visits by eminent Vascular radiologists".

Nikki Christou and other AVM sufferers will hopefully benefit from existing and future breakthroughs that have come about solely due to research funded by The Butterfly AVM charity.

The Royal Free now has an ever-growing busy Vascular department and with frequency of patients comes greater experience and better overall long- term results. This advancement could not have been achieved without our charity's input.

Due to the rarity of AVMs and the lack of understanding the charity has made a concerted effort to provide sufferers with an up to date website which has now been updated to make it more responsive and user friendly and provides a service to inform families about the latest treatments and has raised awareness to an all-time high.

Public benefit

The trustees have given due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake. The trustees have complied with the duty in section 17(5) of the 2011 Charities Act to have due regard to guidance published by the Charity Commission. Details of how the charity's activities are for the public benefit are detailed in this report and the trustees have given due consideration to the Charity Commission guidance on public benefit.

Grantmaking

The charity's grant making policy is to seek out possible causes which may assist in making treatments more successful as well as discovering new treatments and for the trustees to make a majority decision as to whether to support the activity by way of a grant.

REPORT OF THE TRUSTEES For The Year Ended 31 MAY 2019

FINANCIAL REVIEW

Reserves policy

It is the policy of the charity that unrestricted funds which have not been designated for a specific use should be maintained at a level equivalent to between three and six month's administrative and support expenditure. The trustees consider that reserves at this level will ensure that, in the event of a significant drop in funding, they will be able to continue the charity's current activities while consideration is given to ways in which additional funds may be raised. The level of reserves has been maintained throughout the year.

At the end of the year the charity reserves were as follows:

General unrestricted fund: £48,883 Designated fund - Research: £29,277 Designated fund - Treatment: £26,401

During the year the charity received total donations of £80,426.

At the end of the year, the net surplus in funds for the period were £15,043.

The charity continued to maintain healthy bank reserves.

A review of the internal financial controls was undertaken during the year, and were assessed as adequate for the functioning and stewardship of the charity.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is a company limited by guarantee, as defined by the Companies Act 2006. It is controlled by its governing documents which are the memorandum and articles of association.

Recruitment and appointment of new trustees

The method of recruiting and appointing trustees is by majority decision of the trustees currently in office.

None of the Trustees has any beneficial interest in the company. All the trustees are members of the company and guarantee to contribute £1 in the event of a winding up.

Organisational structure

Mr G Christou is the operational manager of the charity.

Decisions are taken with a majority vote amongst the trustees.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number 08061944 (England and Wales)

Registered Charity number 1149170

Registered office 869 High Road London N12 8QA

Trustees Mr G Christou Director Mr G S Georgiou Director Mr K Perifimou Director

Independent Examiner

Mr Philip Onissiphorou FCCA ACA G. George Associates 12 Gateway Mews Ring Way London N11 2UT

REPORT OF THE TRUSTEES For The Year Ended 31 MAY 2019

This report has been prepared in accordance with the special provisions of Part 15 of Companies Act 2006 relating to small companies.

Approved by order of the board of trustees on 25th February 2020... and signed on its behalf by:

Mr G Christou - Trustee

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF THE BUTTERFLY AVM CHARITY LIMITED

Independent examiner's report to the trustees of The Butterfly AVM Charity Limited ('the Company') I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 May 2019.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

Independent examiner's statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

- 1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
- 2. the accounts do not accord with those records; or
- the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
- 4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Mr Philip Onissiphorou FCCA ACA G. George Associates 12 Gateway Mews Ring Way London N11 2UT 26 FEB 244 RY 20 20 Date:

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STATEMENT OF FINANCIAL ACTIVITIES For The Year Ended 31 MAY 2019

	Notes	Unrestricted funds £	Restricted fund £	2019 Total funds £	2018 Total funds £
INCOME AND ENDOWMENTS FROM Donations and legacies	2	80,426	-	80,426	95,163
Investment income	3	126	-	126	15
Total		80,552	-	80,552	95,178
EXPENDITURE ON Raising funds	4	18,628	-	18,628	18,545
Charitable activities Treatment Funding - Designated Research Funding - Designated Treatment Funding - Restricted General Treatment		18,631 27,975 - 275	-	18,631 27,975 275	30,385 27,432 1,000
Total		65,509		65,509	77,362
NET INCOME		15,043		15,043	17,816
RECONCILIATION OF FUNDS					
Total funds brought forward		89,518	-	89,518	71,702
TOTAL FUNDS CARRIED FORWARD		104,561	-	104,561	89,518

BALANCE SHEET 31 MAY 2019

CURRENT ASSETS	Notes	Unrestricted funds £	Restricted fund £	2019 Total funds £	2018 Total funds £
Debtors Cash at bank	9	3,816 100,745		3,816 100,745	275 89,243
		104,561	-	104,561	89,518
NET CURRENT ASSETS		104,561	5	104,561	89,518
TOTAL ASSETS LESS CURRENT LIABILITIES		104,561	-	104,561	89,518
NET ASSETS		104,561		104,561	89,518
FUNDS Unrestricted funds:	10				
General fund Designated fund - Great Ormond Street Research				48,883 29,277	48,840 29,277
Designated fund - Nikki Christou Treatment				26,401	11,401
				104,561	89,518
TOTAL FUNDS				104,561	89,518

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 May 2019.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 May 2019 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

These financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies regime.

The financial statements were approved by the Board of Trustees on 25th February 222. and were signed on its behalf by:

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Mr G Christou - Trustee

-----Mr G S Georgion Trustee

The notes form part of these financial statements

NOTES TO THE FINANCIAL STATEMENTS For The Year Ended 31 MAY 2019

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

The charity is a private limited company registered in the UK and limited by guarantee. Details of the company registered office and place of operations are detailed in the trustees report.

The trustees are members of the company and guarantee to contribute £1 in the event of a winding up.

The charitable company has taken advantage of the following disclosure exemptions in preparing these financial statements, as permitted by FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland':

the requirements of Section 7 Statement of Cash Flows.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

Taxation

The charity is exempt from corporation tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Governance costs

Governance costs for the charity have been assessed and some of these are considered to be more in line with costs for raising funds for the charity as opposed to being strictly for the governance of the charity. These have been adjusted as per the transitional FRS 102 statements.

NOTES TO THE FINANCIAL STATEMENTS - continued For The Year Ended 31 MAY 2019

2. DONATIONS AND LEGACIES 2019 2018 Unrestricted Restricted Total funds funds Total funds funds £ £ £ f Donations 80,426 80,426 95,163 3. INVESTMENT INCOME 2019 2018 Unrestricted Restricted Total funds funds Total funds funds £ £ £ £ Deposit account interest 126 126 15 -

4. RAISING FUNDS

5.

Raising donations and legacies

Events Charity awareness Support costs	Unrestricted funds £ 15,408 1,205 2,015 18,628	Restricted funds £ - - -	2019 Total funds £ 15,408 1,205 2,015 18,628	2018 Total funds £ 15,440 2,043 1,062 18,545
GRANTS PAYABLE				
Research Funding - Designated			2019 £ 27,975	2018 £ 30,385

The total grants paid to institutions during the year was as follows:

	31.5.19	31.5.18
Great Ormond Street Hospital	£ 27,975	£ 30,385

The above "Grants to institutions" is to Great Ormond Street Hospital (GOSH) for research into the AVM condition. £27,975 was paid for research on 30th April 2019.

6. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 May 2019 nor for the year ended 31 May 2018.

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 May 2019 nor for the year ended 31 May 2018.

NOTES TO THE FINANCIAL STATEMENTS - continued For The Year Ended 31 MAY 2019

7. MATERIAL TRANSFERS

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A transfer of £15,000 was made in the year, by agreement of the trustees, from the Unrestricted general fund to the Designated fund for the treatments of Miss Nikki Christou.

8. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

		Unrestricted funds £	Restricted fund £	Total funds
INCOME AND ENDOWMENTS FROM		Ľ.	L	£
Donations and legacies		70,398	24,765	95,163
Investment income		15	-	15
Total		70,413	24,765	95,178
EXPENDITURE ON Raising funds		18,545	-	18,545
Charitable activities Research Funding - Designated		20.005		
Treatment Funding - Restricted		30,385	27,432	30,385 27,432
General Treatment		1,000		1,000
Total		49,930	27,432	77,362
NET INCOME/(EXPENDITURE)		20,483	(2,667)	17,816
Transfers between funds		11,401	(11,401)	-
Net movement in funds		31,884	(14,068)	17,816
RECONCILIATION OF FUNDS				
Total funds brought forward		57,634	14,068	71,702
TOTAL FUNDS CARRIED FORWARD		89,518		89,518
DEBTORS: AMOUNTS FALLING DUE WITH	IN ONE YEAR		2019	2018
Other debtors			£	£
Prepayments			- 3,816	275
				075
			3,816	275
MOVEMENT IN FUNDS				
		Net movement	Transfers between	At
	At 1.6.18	in funds	funds	31.5.19
	£	£	£	£

	At 1.6.18 £	in funds £	funds £	31.5.19 £
Unrestricted funds General fund Designated fund - Great Ormond Street	48,840	15,043	(15,000)	48,883
Research Designated fund - Nikki Christou Treatment	29,277 11,401	-	15,000	29,277 26,401
	89,518	15,043	-	104,561
TOTAL FUNDS	89,518	15,043		104,561

NOTES TO THE FINANCIAL STATEMENTS - continued For The Year Ended 31 MAY 2019

10. MOVEMENT IN FUNDS - continued

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Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds	~	~	~
General fund Designated fund - Great Ormond Street	33,946	(18,903)	15,043
Research	27,975	(27,975)	-
Designated fund - Nikki Christou Treatment	18,631	(18,631)	-
	80,552	(65,509)	15,043
TOTAL FUNDS	80,552	(65,509)	15,043

Comparatives for movement in funds

	At 1.6.17 £	Net movement in funds £	Transfers between funds £	At 31.5.18 £
Unrestricted funds				
General fund	56,357	20,483	(28,000)	48,840
Designated fund - Great Ormond Street	4 077		~~~~~	~~~~~
Research	1,277	-	28,000	29,277
Designated fund - Nikki Christou Treatment	-		11,401	11,401
Restricted funds	57,634	20,483	11,401	89,518
Nikki Christou Treatment Fund	14,068	(2,667)	(11,401)	-
TOTAL FUNDS	71,702	17,816	-	89,518

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds General fund	70,413	(49,930)	20,483
Restricted funds Nikki Christou Treatment Fund	24,765	(27,432)	(2,667)
TOTAL FUNDS	95,178	(77,362)	17,816

NOTES TO THE FINANCIAL STATEMENTS - continued For The Year Ended 31 MAY 2019

10. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined position is as follows:

	At 1.6.17 £	Net movement in funds £	Transfers between funds £	At 31.5.19 £
Unrestricted funds	-		_	
General fund	56,357	35,526	(43,000)	48,883
Designated fund - Great Ormond Street				and the Received
Research	1,277	-	28,000	29,277
Designated fund - Nikki Christou Treatment	-	-	26,401	26,401
	F7 004		44.404	104 504
Destricted funds	57,634	35,526	11,401	104,561
Restricted funds Nikki Christou Treatment Fund	14,068	(2,667)	(11,401)	-
TOTAL FUNDS	71,702	32,859	-	104,561

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	104,359	(68,833)	35,526
Designated fund - Great Ormond Street			
Research	27,975	(27,975)	-
Designated fund - Nikki Christou Treatment	18,631	(18,631)	-
	150,965	(115,439)	35,526
Restricted funds			
Nikki Christou Treatment Fund	24,765	(27,432)	(2,667)
	475 700	(1.10.074)	
TOTAL FUNDS	175,730	(142,871)	32,859
	the second se		

Last years comparative restricted fund was for the funding received from the NHS for the treatment of Miss Nikki Christou using Ethanol Embolisation/Sclerotherapy treatments. These treatments have now ceased.

The designated funds represent funds that have been set aside out of unrestricted funds by the trustees for specific purposes.

The Great Ormond Street Research Fund is for the grant payments for research being undertaken by Great Ormond Street Hospital into the AVM condition.

The Nikki Christou treatment fund is for a grant for further and ongoing treatments on Miss Nikki Christou's AVM condition.

Transfers between funds

A transfer of £15,000 was made in the 2019 financial year and was agreed by the trustees from the Unrestricted general fund to the Designated fund to cover medical fees for Miss Nikki Christou. The balance of the Designated fund at the year end was £26,401.

NOTES TO THE FINANCIAL STATEMENTS - continued For The Year Ended 31 MAY 2019

11. OTHER FINANCIAL COMMITMENTS

The charity has agreed to pay £87,500 over the next 3.5 years for the ongoing research into the AVM condition. £29,277 has been designated for this purpose and has been reflected as such in these accounts.

12. RELATED PARTY DISCLOSURES

The beneficiary, Miss Nikki Christou, is the daughter of the trustee Mr George Christou.

A designated fund for the ongoing treatments of Nikki Christou exists at the year end and its closing balance was £26,401.

A transfer of £15,000 was made in the 2019 financial year and was agreed by the trustees from the Unrestricted general fund to the Designated fund to cover treatments for Miss Nikki Christou.