# **REPORT AND FINANCIAL STATEMENTS**

FOR THE YEAR ENDED 31 DECEMBER 2017

Charity No. 1149400 (England and Wales)



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# **LEGAL AND ADMINISTRATIVE INFORMATION**

Trustees A Mifsud (Chair)

C Codner R Mifsud

Charity Number 1149400

Principal Address MPT House

Cobbs Wood Industrial Estate

Brunswick Road

Ashford

Kent TN23 1EL

Independent Examiner M A Wilkes FCA

Wilkins Kennedy Greytown House 221 - 227 High Street

Orpington Kent BR6 0NZ

Banker Lloyds Bank PLC

29 Bank Street

Ashford

Kent TN24 8SS

#### REPORT OF THE TRUSTEES

The trustees present their report and examined financial statements of the charity for the year ended 31 December 2017. The Trustees have adopted the provisions of the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" (FRS 102) in preparing the annual report and financial statements of the charity.

The financial statements have been prepared in accordance with the accounting policies set out in notes to the accounts and comply with the charity's governing document, the Charities Act 2011 and 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 published on 16 July 2014, as amended by bulletin 1.

#### **Public Benefit Statement**

The trustees confirm that they have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the Trust's aims and objectives and in planning future activities.

#### **Objectives and Activities**

The objectives of the charity are:

The relief of sickness and promotion of the health of children suffering with DIPG brain tumours in particular, but not exclusively by:

- 1 Promoting public awareness of the signs and symptoms of brain tumours in children and young people;
- 2 Providing funding for the development of research into practical applications for the prevention, treatment and cure of children's DIPG brain cancer.

'Our mission is to raise awareness and contribute much needed funds for Children's DIPG Brain Tumour Research'

This is our primary objective which guides our work and drives the charity forward on a daily basis.

#### What is DIPG?

DIPG or 'Diffuse Intrinsic Pontine Glioma' is the MOST FATAL form of childhood brain cancer which grows in the 'pons' area of the brainstem. DIPG presents a huge challenge as it is only in recent terms that we have begun to biopsy this tumour safely which is finally yielding information to researchers in order to create the development of much needed targeted treatments based on an individual tumour profile. Currently DIPG is considered 'terminal at diagnosis' and represents around 15% of all brain cancer diagnoses in children. 40 UK children are affected every year. The average survival time from diagnosis is only 9 months.

Our 'mission' is to RAISE awareness and contribute much needed funds for children's DIPG brain tumour research which is so woefully underfunded. The facts are inescapable and there is no direct Government funding for DIPG research, we simply have to provide the pre-clinical research required for translation and adoption within the clinical setting. As with any medical research development it is a long and costly endeavour.

During 2017 two funding proposal for grants were accepted, the charity also continued to monitor any existing grants/projects and review in detail the clinical landscape and funding opportunities attached to emerging therapies, still identifying new potential trends and funding needs. We have continued to build on the links with our DIPG 'community' with sadly increasing contacts from more affected families for advice regarding treatment and fundraising, our networks and contact base within the research community has also expanded.

## **Grant making policy**

Abbie's Army are committed to raising funds and commissioning high quality and innovative medical research to find a cure for DIPG. Grants can only be funded if they fulfil our own specific criteria for funding research and if they pass the review of our Scientific Advisory panel. Our research 'strategy' can be found published online on our new website.

#### REPORT OF THE TRUSTEES

#### **Objectives and Activities (continued)**

We are committed to providing targeted and biologically relevant study, which contributes to combinational approaches as research is beginning to show this will be needed to be curative. We favour approaches that are medically progressive and translational with clear path to informing future clinical trials, ultimately, we have to make the best decision for our donors with the limited resource that we have. Quite simply put the more we have the more we can achieve.

We are committed to providing targeted and biologically relevant study, which contributes to combinational approaches as research is beginning to show this will be needed to be curative. We favour approaches that are medically progressive and translational with clear path to informing future clinical trials, ultimately, we have to make the best decision for our donors with the limited resource that we have. Quite simply put the more we have the more we can achieve.

Abbie's Army positively welcomes the opportunity to combine efforts with other charities and fundraising groups to make a wider impact.

#### Charitable objects for public benefit

In setting our objectives and planning our activities our Trustees have considered the Charity Commission's general guidance on public benefit.

As Trustees we take very seriously the responsibility to fulfil our duties, serve our objectives and deliver for public benefit our goals for supporting the effective treatment for children's DIPG brain cancer research.

#### **Achievements and Performance in the Year**

Throughout 2017 the charity continued to broaden its contact base, aiming to promote its profile locally and increase awareness throughout its UK reach using the free advertising available with social media we were fortunate to receive many public donations, mostly the result of numerous personal fundraisers taking on their own variety of events and sponsored challenges.

We also took some time to develop and launch a new charity website, (covered by a sponsor) which sets out much more clearly the information needed in all areas to communicate effectively, not only with supporters but particularly for newly diagnosed families. Along with providing a more comprehensive resource for all kinds of DIPG related information, we can host support for fundraisers to access online, reducing the amount of manual communication. We can also showcase our funded research history and grant awards as they happen, with all the latest charity news providing greater transparency to the donor. It was time well spent as most importantly for families and others to choose to join with us the website has to reflect our knowledge and capability.

We also became registered with the 'Fundraising Regulator' during the year for additional donor confidence, and accept the commitment made to donors and the public by adhering to the 'Fundraising Promise' Those who register with the Regulator agree to maintain high standards and ensure their fundraising is legal, open, honest and respectful at all times. Those fundraising on our behalf as appointed representatives of the charity are all made aware of what is acceptable.

We were fortunate again to have several connections with local companies, clubs and groups who elected us for support and donated by way of several fundraising ideas throughout the year and sponsorship from one off events. Our main sponsor (Dunlop BTL Ltd) also extended to us a temporary leasehold of premises for activities, whilst vacant premises were on the open market for sale during the year.

#### REPORT OF THE TRUSTEES

# Achievements and Performance in the Year (continued) Grants Awared and Review of 2017

In July 2017 Abbie's Army announced its largest grant award to date, to Stanford University, California in the US. After careful review by our scientific advisories and considerable discussions and negotiations with Michelle Monje, the study entitled:

'Towards a multi-pronged approach for DIPG therapy targeting BDNF-TrkB signalling in the DIPG micro environment'- Stanford, \$270,000 (over two years £102,000 (\$132,617) paid July 2017 balance 2018 on review)

Successful treatment of diffuse intrinsic pontine glioma (DIPG) will likely require a multi-pronged approach, targeting intrinsic vulnerabilities of DIPG cells, blocking key signals from the micro environment of the developing childhood brain that fuel DIPG growth, and directing the immune system to attack the cancer.

DIPG hijacks mechanisms of development and plasticity in the childhood brain. Neuronal activity is a key regulator of brain development and plasticity, and the Stanford lab have recently shown that active neurons in the tumour micro environment robustly promote DIPG growth.

A growth factor called "brain-derived neurotrophic factor" (BDNF) is secreted in response to brain activity and plays numerous roles in childhood brain development.

BDNF identified as a molecule that promotes DIPG proliferation and therefore likely that DIPG subverts BDNF signalling to promote cancer growth.

In proposed experiments, we seek to determine the therapeutic potential of blocking BDNF signalling in DIPG, cutting off what we hypothesize is a key micro environmental factor fuelling DIPG growth.

The majority of the proposal focuses on BDNF, a leading candidate for micro environmental therapy in DIPG. Parallel work however from the Stanford group has also focused on developing an effective immunotherapy strategy for DIPG and included in the proposed project are a discrete set of experiments seeking to advance our mechanistic understanding of a promising immunotherapeutic strategy using chimeric antigen receptor T cells (CAR-T cells). Our contribution has aided the publishing of a paper in the journal 'Nature' regarding the use of this GD2 directed CAR-T cell treatment in DIPG cell lines, the data was astounding. A GD2 directed CAR-T therapy is now scheduled for pilot clinical trial in children for Spring 2019 at Stanford.

Ultimately, the goal is to identify and combine the optimum therapeutic strategies involving immunotherapy and more synergistic targeting of the micro environmental determinants of DIPG growth. Hitting the cancer from different angles, will move us closer towards the goal of defeating DIPG.

In the context of so many other developments coming to fruition at Stanford the Trustees felt there is great potential and every reason to be hopeful for the development of an effective combination therapy for DIPG here, with a clear path to implementation in clinical trial.

# PDX 'Avatar' Analysis for UK BIOMEDE DIPG trial samples – Institute of Cancer Research, Sutton UK 2017 Onwards.

We expressed a great interest in working alongside The Institute of Cancer Research and Prof Chris Jones - a previous recipient of Abbie's Army funding, on a much broader analysis of the biopsy samples being taken for those enrolled on the newly opened UK trial for DIPG known as BIOMEDE.

#### REPORT OF THE TRUSTEES

#### Achievements and Performance in the Year (continued)

This commenced in the UK in April, 2017 and is now open at most UK treating centres as part of a European roll out, it is the only 'adaptive' clinical trial currently open in the UK and in a first of it's kind for DIPG involves upfront biopsy and stratification of patients to various treatment arms of the trial dependent upon their genetic mutation. This determines which drug they will initially receive, and so most importantly for the first time they will be trialled against a target they know is actually 'present' in their tumour biology. At the same time a key feature of the BIOMEDE trial is the introduction of experimental agents at relapse should an appropriate 'target' be found during the molecular analysis and broader sequencing of the individual child's tumour.

To build on this feature, we have pledged funding on a 'per patient' basis to establish 'Patient Derived Xenografts' or PDX models (also known as avatars) of individual patient disease for screening and testing in vitro and vivo. These are all drug screened and the most efficacious agents identified will be fed back to the treating clinicians in the individual treatment centres of the patient.

This is a huge challenge, but biopsy has a hugely important role to play, indeed throughout the evolution of DIPG disease as it adapts to single agent therapy and creates resistance.

It is hoped this study can highlight the most effective combinational therapies as well as validate the clinical use of PDX models in DIPG treatment. All data will also be fed back to Registry sites for research sharing.

Abbie's Army has initially limited this funding to £100,000 and will review it's potential with the results from sampling obtained. As at the end of 2017 a total of 12 patients had been processed with an amount funded of £30,000. Modelling has been successful in a percentage of cases and has identified additional targets that are advised for clinical use.

## Plans for the future

The charity will continue to be driven by its mission statement, its aims and objectives and ensure the best practice is delivered for our supporters.

We will continue to plan events to fund raise and seek out opportunities to recruit charity partners to secure sustainable and regular income streams. We are fully aware that fundraising methods can have an impact on public opinion and the reputation of our charity and we endeavour to self-govern effectively.

As DIPG is a specific and rare childhood cancer affecting low numbers it will remain the core of our strategy to attract and aim to invite other affected families who may want to fund raise for research purposes but cannot see the benefit in the duplication of another charity for that same purpose. We have already received support of other families who have joined us for their part to play in making an impact on the disease, collaboration is to be encouraged and in that sense, we will proceed more quickly.

We will continue to extend our use of social media including Facebook and Twitter as an integral part of our communication campaign to continue spreading DIPG awareness and attract opportunities both individual and commercial. There are currently no plans to pursue the addition of paid fundraisers or PR advertising to increase revenues.

#### **Financial Review**

Income for the year amounted to £118,696 (2016: £136,832) which comes from donations by individuals and companies.

Expenditure for the year amounted to £219,544 (2016: £18,091). During the year, grants were paid amounting to £202,002 (2016: £nil) to aid the research into DIPG.

This resulted in a deficit for the year of £100,848 (2016: surplus £118,741).

#### REPORT OF THE TRUSTEES

#### **Reserves Policy**

In accordance with the Charity Commission guidance, the trustees review on a regular basis the level of income reserves that it considers appropriate. At 31 December 2017, the trustees consider it appropriate to hold no free reserves and have deemed all funds as designated funds, in support of its charitable objectives. The designated reserves at 31 December 2017 amounted to £119,871 (2016: £220,719).

#### **Investment Policy**

The investments held by the charity were inherited from previous trustees and committees. No change is foreseen by the current Board of Trustees.

#### Risk management

The charity Trustees have given consideration to the major risks to which the charity is exposed and satisfied themselves that those systems or procedures are established in order to manage those risks.

As a small charity working within our structure and environment our situation is not currently complex, we must however address risk particularly in relation to finances as it arises with monitoring and evaluation. Our emphasis is firmly on fund raising, so maintaining transparency and full disclosure to prevent any loss of donor confidence and adverse publicity is paramount.

#### Structure

The charity name 'Abbie's Army' is governed by charitable Trust Deed dated 21 October 2012 which was entered onto the Register of Charities on 22 October 2012 under the registration of 1149400.

#### **Governance and Management**

The Trustees of Abbie's Army are responsible for the general control and management of the administration of the charity.

During the year the following were Trustees of the charity:

A Mifsud (Chair)

C Codner

R Mifsud

Apart from the first trustees every trustee must be appointed by a resolution of the trustees passed at a special meeting called by the appointed chairman or by at least two trustees. The governing document does not specify a minimum or maximum number of trustees.

Abbie's Army is a very small parent led charity. Its governance remains solely the responsibility of the existing member Trustees who have first-hand experience of DIPG, research knowledge of the clinical landscape and abilities to lead the charity's work.

The Trustees govern the activities of the charity and drive it forward on a daily basis, family members and friends give up their time voluntarily to administer and organise charity events, and ensure the fulfilment of our aims and objectives for 'public benefit'.

No one in connection with Abbie's Army receives payment or benefits of any kind.

Abbie's Army is grateful for the advice and assistance from a number of individuals in the research community. Our own small 'Advisory panel' is comprised of leading experts on childhood brain cancer. They review any grant applications and make recommendations to ensure that Abbie's Army is fulfilling its remit to fund the most promising DIPG research projects, with its limited resource.

#### REPORT OF THE TRUSTEES

#### Statement of Trustees' Responsibilities

The trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England & Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources of the charity for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP 2015 (FRS 102);
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to assume that the charity will continue in business;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by the trustees and signed on their behalf by:

Mrs A Mifsud Trustee

Date: 21 October 2018

#### INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES

I report on the accounts of the Charity for the year ended 31 December 2017, which are set out on pages 9 to 13.

#### Responsibilities and basis of report

As the charity Trustees you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

I have completed my examination. I confirm that no material matters except that referred to in the previous paragraph have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 1 accounts records were not kept in respect of the Trust as required by section 130 of the Act; or
- 2 the accounts do not accord with those records; or
- 3 The accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 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.

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.

M A Wilkes FCA Wilkins Kennedy Accountants 22 October 2018 Greytown House 221 - 227 High Street Orpington Kent BR6 0NZ

# STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2017

		Unrestricted funds	
	Notes	2017 £	2016 £
Income from:			
Donations		118,696	136,832
Total income	<del>-</del>	118,696	136,832
Expenditure on:			
Cost of raising funds			
Costs of event staging and entry fees		4,818	13,813
Costs of merchandise		3,879	-
Other Just Giving costs and membership		483 3,406	1,439 2,839
Cost of charitable activities			
Grants awarded	2	202,002	-
Website and website hosting costs		2,100	-
Rates		2,756	-
Depreciation		100	-
Total expenditure	-	219,544	18,091
Net movement in funds		(100,848)	118,741
Funds brought forward 1 January 2017		220,719	101,978
Funds carried forward 31 December 2017	- =	119,871	220,719

# BALANCE SHEET AS AT 31 DECEMBER 2017

	Notes	2017		2016	6
		£	£	£	£
Fixed Assets					
Tangible assets	3		16,501		-
Current Assets					
Debtors	4	2,331		926	
Cash at bank and in hand		171,039		219,793	
		173,370		220,719	
Creditors: amounts falling due within one year	5	(70,000)			
Net current assets			103,370		220,719
Net assets		- -	119,871	- -	220,719
E I					
Funds			440.074		000 740
Designated funds - DIPG research		=	119,871	=	220,719

Approved by the Board of trustees on 21 October 2018 and signed on their behalf by:

Mrs A Mifsud R Mifsud Trustee Trustee

# NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2017

#### 1 ACCOUNTING POLICIES

#### 1.1 Basis of preparation

Abbie's Army is a registered charity with the Charity Commission in the United Kingdom. The address of the registered office is given in the charity information on page 1 of these financial statements. The nature of the charity's operations and principal activities detailed in the Trustees' Annual Report on page 2 under the heading 'Objectives and activities'.

The charity constitutes a public benefit entity as defined by FRS 102. The financial statements have been prepared in accordance with 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 (FRS 102) issued on 16 July 2014 as amended by Bulletin 1, the Financial Reporting Standard applicable in the United Kingdom (FRS 102), the Charities Act 2011, and UK Generally Accepted Practice as it applies from 1 January 2015.

The financial statements are prepared on a going concern basis under the historical cost convention, modified to include certain items at fair value. The financial statements are prepared in sterling which is the functional currency of the charity and rounded to the nearest £.

The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all years presented unless otherwise stated.

#### 1.2 Funds accounting

Unrestricted general funds are funds which can be used in accordance with the charitable objects at the discretion of the Trustees.

Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose.

#### 1.3 Income

All income is included in the Statement of Financial Activities when the charity is entitled to the income and the amount can be quantified with reasonable accuracy. The following specific policies are applied to particular categories of income:

- Voluntary income including donations and gifts is included in full in the Statement of Financial Activities when receivable.

#### 1.4 Expenditure

Expenditure is accounted for on an accruals basis. The irrecoverable element of VAT is included with the item of expense to which it relates.

- Costs of generating funds are those costs incurred in attracting voluntary income and staging and entering fundraising events.
- Grants payable are accounted for once the trustees have reviewed and discussed applications
- Governance costs include those incurred in the governance of the charity and are primarily associated with constitutional and statutory requirements.

### 1.5 Tangible fixed assets

Individual fixed assets costing £500 or more are capitalised at cost. Depreciation is provided at rates calculated to write off the cost of the assets over their

Alpacas Not Depreciated Fixtures and Fittings 20% Straight line

### 1.6 Animals

The cost of acquisition of animals is capitalised to the extent a value can be placed upon them. Subsequent births and deaths are not included on the Balance Sheet.

# NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2017

#### **ACCOUNTING POLICIES**

## 1.7 Debtors and creditors receivable / payable within one year

Debtors and creditors with no stated interest rate and receivable or payable within one year are recorded at transaction price. Any losses arising from impairment are recognised in expenditure.

#### 1.8 Tax

The charity is an exempt charity within the meaning of schedule 3 of the Charities Act 2011 and is considered to pass the tests set out in Paragraph 1 Schedule 6 Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes.

#### 1.9 Going concern

The financial statements have been prepared on a going concern basis as the Trustees believes that no material uncertainties exist. The Trustees has considered the level of funds held and the expected level of income and expenditure for 12 months from authorising these financial statements. The budgeted income and expenditure is sufficient with the level of reserves for the charity to be able to continue as a going concern

### 1.10 Judgements and key sources of estimation uncertainty

Accounting estimates and judgements are continually evaluated and are based on historical experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances. There are no areas of judgment or key estimations.

2	GRANTS AND DONATIONS PAYABLE			
			2017	2016
			£	£
	Grants to institutions			
	Institute of Cancer Research		100,000	-
	Monje Lab - Stanford University		102,002	-
		_	202,002	-
		F	ixtures and	
3	TANGIBLE FIXED ASSETS	Alpacas	Fittings	Total
		£	£	£
	Cost			
	As at 1 January 2017	-	-	-
	Additions	16,100	501	16,601
	As at 31 December 2017	16,100	501	16,601
	Depreciation			
	As at 1 January 2017	-	-	-
	Charge for the period		100	100
	As at 31 December 2017	-	100	100
	Net Book value			
	As at 31 December 2017	16,100	401	16,501
	As at 31 December 2016	-	-	-

# NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2017

4	DEBTORS	2017	2016
		£	£
	Gift aid receivable	2,217	926
	Prepayments	114	-
		2,331	926
5	CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR	2017	2016
		£	£
	Grants payable	70,000	

#### 6 RELATED PARTY TRANSACTIONS

During the year Mrs A Mifsud paid the following costs, as a donation, on behalf of the charity:

	2017 £	2016 £
Event staging materials	-	797
Advertising	180	619
Insurance to host events	547	-
Subscriptions	62	-
Costs of raising funds including costs of new website and new collection boxes	4,928	-

During the year Dunlop BTL Limited paid £18,460 (2016: £nil) for the purchase of merchandise to raise funds for the charity. R S Mifsud and Mrs A Mifsud are directors of Dunlop BTL Limited.

## 7 STAFF COSTS AND TRUSTEE REMUNERATION

No staff are employed by the charity.

No trustees received remuneration or were reimbursed for expenses incurred during the year (2016: £Nil).

# **8 GRANT COMMITMENTS**

During the year, the charity committed to funding the Monje Lab at Standford University to the value of £210,000. £102,002 has been paid during the year ended 31 December 2017 and the remainder is due to be paid in 2018 following receipt of an interim report.