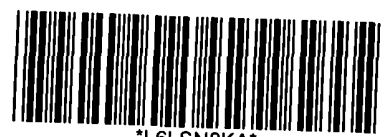


Charity Registration No. 1114367

Company Registration No. 5407899 (England and Wales)

THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))
TRUSTEES' REPORT AND UNAUDITED ACCOUNTS
FOR THE YEAR ENDED 31 MARCH 2017

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THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees

A Flint
L Flint
B Jefferies
J Jefferies
S Heales

Secretary

L Flint

Charity number

1114367

Company number

5407899

Registered office

Airport House
Suite 43-45 Purley Way
Croydon
Surrey
CR0 0XZ

Independent examiner

Ledger Sparks Ltd
Airport House
Suite 43-45 Purley Way
Croydon
Surrey
CR0 0XZ

Bankers

Barclays Bank
Barclays Bank Plc
1 North End
Croydon
Surrey
CR91SX

THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

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THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

TRUSTEES' REPORT

FOR THE YEAR ENDED 31 MARCH 2017

The trustees present their report and accounts for the year ended 31 March 2017.

The accounts have been prepared in accordance with the accounting policies set out in note 1 to the accounts and comply with the trust's [governing document], the Companies Act 2006 and the Statement of Recommended Practice, "Accounting and Reporting by Charities", issued in March 2005.

Structure, governance and management

The trust is a company limited by guarantee, incorporated on 30 March 2005 and registered as a charity on 24 May 2006. The company was established under a memorandum and articles which established the objects and powers of the charitable company and is governed under its articles of association.

The trustees, who are also the directors for the purpose of company law, and who served during the year were:

A Flint
L Flint
B Jefferies
J Jefferies
S Heales

The appointment of Trustees as described in our Memorandum & Articles of Association dated 30th day of March 2005 states that there shall be not less than three trustees. At each AGM one third of the trustees must retire by rotation and may submit for reappointment. The trustees to retire by rotation shall be those longest in office since their last appointment or reappointment. Trustees may recommend additional appointments to the board of trustees.

The Board of Trustees administers the charity. The Board of Trustees meets half-yearly to discuss all aspect of the Charity's business.

The AADC Research Trust is made up of six Trustees are responsible for the strategic direction and policy of the Charity.

The Board of Trustees are from a variety of backgrounds:

Tony and Lisa Flint, who initiated the incorporation of the Trust and being parents to an affected AADC child, are responsible for ensuring that the charity delivers its aims and objectives as specified in its Memorandum & Articles of Association dated 30th day of March 2005. They are responsible for the day to day running of the Charity.

Jacqui and Brian Jefferies, appointed as Trustees, represent the Charity at every level and on a day-to-day basis. Jacqui and Brian are capable of directing the Charity in the unavoidable absence of Tony and Lisa Flint.

Dr Simon Heales PhD, appointed as a Trustee, is a Scientist. In collaboration with the Trusts Medical and Scientific Advisory Members, Dr Heales provides essential direction for the funds raised by the Trust which are made available for AADC Research.

THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2017

The Charity continues to work with its 17 Medical & Scientific Advisory Members which includes 10 international Members.

Clinical and Scientific Professional members are located throughout the World (London, Germany, USA, Spain, Greece, Taiwan, Malaysia and The Netherlands). The Medical and Scientific Advisory Chairman Dr Keith Hyland PhD, from the USA, was the first Scientist to site papers directly relating to AADC deficiency in 1992.

The Board of Trustees or the Medical and Scientific Advisory Members can make a recommendation for the addition of new Medical and Scientific Advisory Member. A vote amongst the Board of Trustees and Medical and Scientific Advisory Members determines the appointment of a new Medical and Scientific Advisory Member.

Each Medical and Scientific Advisory Member is invited for a 2-year term. Every 2 years a Medical and Scientific Advisory Member may be invited back to serve a new 2-year term. All Medical and Scientific Advisory Members have relevant expertise relating to the disease AADC deficiency. The Medical and Scientific Advisory Members aim to meet every other year to discuss all aspects of AADC deficiency.

The Trust has established links with other International AADC support groups, which has proved invaluable to the Charity in establishing improved links within the global community of affected AADC families. The Trust works closely and under guidance from the Medical and Scientific Advisory Members and affiliates itself with the Medical and Scientific Advisory Members and their Workplace.

The trustees has assessed the major risks to which the trust is exposed, and are satisfied that systems are in place to mitigate exposure to the major risks.

Objectives and activities

The main aim and objective of the Trust is to fund AADC Research, in addition to this the Trust aims to raise Global AADC Disease Awareness and Support AADC Affected Children and their Families.

The Trust invites applications for AADC research grants. In consultation with our Medical and Scientific Advisory Members, The AADC Research Trust will only invest in research projects where the results have the potential to offer tangible benefits for those who suffer with AADC deficiency.

Consideration may be give to funding and supporting research and projects by other reputable charities where there may be benefits to sufferers of AADC deficiency.

THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2017

Achievements and performance

Another busy and expensive year for the Trust as it continues to financially support the PhD Studentship at GOSH for the development of AADC Induced Pluripotent Stem Cells. Our student presented her early findings at our 10-year Anniversary Conference held at Lingfield Racecourse in Surrey in May 2016. If successful, these cell lines will vastly improve our understanding of the disease at a molecular level, this project commenced at end of 2014 and will run until 2017/18.

The Trust part funded the creation of a consortium of specialist medical clinical metabolic experts from centres around the world which included two Charity Trustee's. Together they developed and completed an online International Neurometabolic Database (website iNTD www.intd-registry.org). The aim was to produce evidence based clinical guidelines for AADC and all other related diseases that will help standardise treatment and will aid clinicians internationally in the management of these complex diseases. AADC deficiency is the first neurotransmitter disease to be described in such detail and will be used as a template for all other. As a result of this work, a peer review publication was submitted by the iNTD group and successfully published in January 2017. The disease was officially named in this publication using a new acronym AADCd (Aromatic Amino Acid Decarboxylase deficiency).

Finally, detailed guidelines, based on historic and current experiences with the disease, are available online for Professionals and Carers worldwide and can be found here:

<https://ojrd.biomedcentral.com/articles/10.1186/s13023-016-0522-z>.

The Trust held its 3rd International 2-day Conference in May 2016, some sponsorship for this event was received from Agilis Biotherapeutics, Voyager Therapeutics and the SSADH Association, all three companies provided some level of financial support. Clinical and Scientific experts plus AADC affected families presented at this meeting with more than 18 countries being represented overall. A large part of the conference was spent discussing AADC Gene Therapy Trials. A good detailed description of the GT trial was provided both clinically and scientifically by Parkinson's Specialist's Prof Krystof Bankiewicz of USA and Prof Shin-ichi Muramatsu of Japan, Both presented their (differing) versions of the GT procedure. This event cost the Trust in excess of £60,000.

A Landmark Moment in the Treatment of our Disease: The US AADC GT trial finally began in January 2017 in San Francisco. The first AADC child underwent extensive surgery as part of this trial. It will take some time to monitor improvements and outcome to see whether this possible treatment has the ability to dramatically alter the outcome of this disease. As a Charity representative I was able to fly to San Francisco in March 2017 to meet and discuss this pioneering procedure with the Gene Therapy Surgical and Administrative team. During my time there I also visited the hospital surgical unit, ICU wards and the accommodation; where our family's taking part in the trial stay for up to 3 to 6 months post-surgery. During this short visit I had the chance to catch up with our first family who underwent this surgery, 3 months post op, to discuss the triumphs and tribulations associated with this invasive surgery. I also met with 3 more AADC families who live in both San Francisco and Seattle. The second child and third child selected to take part in this trial are expected to undergo surgery in May and September 2017 respectively. These are very exciting times for our group but a painfully slow process for those caring for severely disabled children on a daily basis.

GOSH (Great Ormond Street Children's Hospital) continues to prepare itself for becoming a site for an AADC GT trial following the audit of the vector in Philadelphia to enable the successful importation to GOSH when required. This audit was fully funded by the Trust. An application will be submitted to funding bodies in the UK for consideration and we must await the outcome of these decisions before continuing with this UK trial opportunity. This pioneering treatment could still set the benchmark for the treatment of all other neurotransmitter diseases in the future.

The Trust received an application to fund a research project on exploring the AADC genetic variations which was approved and commenced in September 2015 completing in September 2016. The Italian Scientific group presented their interim findings relating to this project at our May 2016 Conference and have subsequently published on the subject. This research is ongoing with further interest and funding being negotiated with a Biotherapeutics Company in the USA. Identifying mutations and understanding their molecular effect on the AADC gene may help us to design treatment strategies tailored to a suffering child's individual severity and needs. I am hoping to visit the Lab and scientists in Italy sometime in 2017.

THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2017

In September 2016 a grant was approved for Dr Roser Pons in Greece. Dr Pons is an expert on AADC deficiency and related neurotransmitter disorders and one of the Trust's M&S Advisory members. These funds will be used over a 12-month period, starting in 2017, to assist in the development of a 'symptom scale system' relating to AADC deficiency and dystonia. This is likely to be ongoing and will be approved on a yearly basis depending on the availability of funds. Dr Pons will collaborate closely with the Italian Group to consolidate findings.

The AADC disease animation was completed and launched at our 2-day Conference and shown at our 10 year anniversary event in May 2016. The Trust held a GALA Ball fundraiser during its 2-day Conference which was attended by 250 people and raised a substantial amount which went towards the cost of our conference. The animation was hugely successful amongst our medics and families and is being used as a training tool for medical trainees around the world. Following the help of some of the Trust's medical advisory team we have since translated this animation in Italian and German and during 2017/18 we will finish Dutch, Spanish, Polish and Japanese. We will continue to translate this into multiple languages to be used as a useful tool when children are first diagnosed.

The Trust has provided emotional, educational and financial support to families affected by this disease. Grants for equipment, therapy and other related needs are dependant on the availability of funds at the time of application. In May 2017 we will launch our first Awareness Campaign Week 'Teddy Wears BLUE' which will last a week. We will try and engage families from all around the World to take part and encourage them to help in our efforts to raise money for research projects for the benefit of all our children. We hope this will be an annual event. Funds are continually being raised and where possible saved, in preparation for our 4th International 2-day Conference in November 2018.

The Trust continues to be involved with many state of the art scientific research methods which hold potential for many other neurological diseases. Its lack of funds still hampers research opportunities and we are still relying on the submission of research applications to alternative funding bodies by our Medical & Scientific Advisory Members to further advance our understanding of this disease.

The Trust has acquired a small shop front premises which was obtained on a 'non-contract' rental basis during 2016 located a couple of doors down from its charity shop & tea room and increases our premises to 3 sites, all within the same vicinity and all with the same Landlord. This shop front is situated at the front of the donation drop off premises previously acquired. By moving the office out of the Tea Room and Boutique we have been able to expand our seating area in the Tea Room by making a dedicated room for larger groups visiting us. The 'indoor' Garden Room is suitable for parties of up to 18 and proving to be very popular. Afternoon Tea's for groups are a favourite for Birthday's, Hen Celebrations, Baby showers etc... this room has proved popular and a great addition to our Tea Room and Boutique.

Our staff level has increased and the local community continues to be actively involved with large groups of volunteers regularly donating their time to help our cause. The newly acquired shop is a base for the Charity's office as well as displaying and running its newest fundraising venture, the hiring of props and vintage china for weddings and events etc to the public. The china has been donated by customers and stored during the previous 5 years until such time there was enough to hire for large scale events

THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2017

In the coming years we will continue to work hard and fundraise and follow through with important topics such as:

Improve and simplify the complex diagnostic procedure using a simple blood spot method or using urine markers if they can be made reliable.

Sponsoring AADC Gene Therapy workshops in the UK, Europe and USA, which is still a priority, whereby the selection process, pre and postoperative care plus overall risk versus benefit will be explained to those families considering the procedure.

Concentrating on developing a better understanding amongst medical professionals, particularly at local hospital level, in order that children are diagnosed younger. Simplifying the diagnostic procedures will greatly help, as medical costs will be reduced, tests less invasive and referrals to specialist centres more informed.

A project exploring whether AADC children and long-term use of medications can have an adverse effect on their neuropsychological development, plus explore the neuropsychology of carriers (parents and siblings) to see if they are symptomatic as some family's report.

A project discovering the relationship between Serotonin, the Gut and Autonomic Dysfunction and how it impacts on pain and symptoms of AADC deficiency.

Another project developing multiple therapy strategies unique to our group after the onset of medications. Standardised methods may improve the uptake of medication and physical ability. Therapy of interest initially is physio, occupational and speech & language.

AADC deficiency continues to advocate, accelerate & improve treatment strategies for all other unsupported rare neurotransmitter diseases.

Financial review

Expenses are kept to a minimum and the Charity, where possible, accepts the support and generosity of all those who offer. The Trust runs three arms of one account required for the day to day running of its business; one current account, one step saver account and one charity shop account.

- A Current Account; for all business not associated with our Charity shop, funds are kept to a £2,500 minimum.
- A Charity Shop Account; for day to day cash flow relating to all sales and overheads, funds are kept to a £2,500 minimum.
- A Step Saver Account; funds are transferred to this savings account when they exceed the £2,500 minimum described above and represent available funds for projects the Trust is considering. A minimum of £5,000 is available at all times to support both accounts above should it be required.

It is the policy of the trust 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 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 trust's current activities while consideration is given to ways in which additional funds may be raised. This level of reserves has been maintained throughout the year.

On behalf of the board of trustees

A Flint

Trustee

Dated: 22 December 2017



THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

INDEPENDENT ACCOUNTANTS' REPORT TO THE MEMBERS ON THE UNAUDITED ACCOUNTS OF THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

I report on the accounts of the trust for the year ended 31 March 2017, which are set out on pages 7 to 12.

Respective responsibilities of trustees and reporting accountants

The trustees, who are also the directors of The AADC Research Trust (formerly PND Association (UK)) for the purposes of company law, are responsible for the preparation of the accounts. The 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. The charity's gross income exceeded £250,000 and I am qualified to undertake the examination being a qualified member of Chartered Certified.

Basis of opinion

My examination was carried out in accordance with the 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 you as 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.

Opinion

In our opinion:

- (a) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.
- (b) which gives me reasonable cause to believe that in any material respect the requirements:
 - (i) to keep accounting records in accordance with section 386 of the Companies Act 2006; and
 - (ii) to prepare accounts which accord with the accounting records, comply with the accounting requirements of 396 of the Companies Act 2006 and with the methods and principles of the Statement of Recommended Practice: Accounting and Reporting by Charities;



Ledger Sparks Ltd

Chartered Certified Accountants
Reporting Accountants
Airport House
Suite 43-45 Purley Way
Croydon
Surrey
CR0 0XZ

Dated: 22 December 2017

THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2017

	Notes	2017 £	2016 £
<u>Incoming resources from generated funds</u>			
Donations and legacies	2	29,178	20,830
Grants and Sponsorship		10,744	-
Investment income	4	13	19
		<u>39,935</u>	<u>20,849</u>
Incoming resources from charitable activities	3	291,216	212,742
Total incoming resources		<u>331,151</u>	<u>233,591</u>
<u>Resources expended</u>			
Costs of generating funds			
Costs of generating donations and legacies		4,866	-
		<u>4,866</u>	<u>-</u>
Net incoming resources available		<u>326,285</u>	<u>233,591</u>
Total charitable expenditure		<u>339,999</u>	<u>179,693</u>
Governance costs		4,379	5,481
Total resources expended	5	<u>344,378</u>	<u>185,174</u>
Net (expenditure)/income for the year/ Net movement in funds		<u>(13,227)</u>	<u>48,417</u>
Fund balances at 1 April 2016		<u>80,595</u>	<u>32,180</u>
Fund balances at 31 March 2017		<u><u>67,368</u></u>	<u><u>80,597</u></u>

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

BALANCE SHEET

AS AT 31 MARCH 2017

	Notes	2017 £	£	2016 £	£
Fixed assets					
Tangible assets	8		7,084		-
Current assets					
Stocks		9,033		9,033	
Debtors	9	1,611		7,151	
Cash at bank and in hand		55,783		68,853	
		66,427		85,037	
Creditors: amounts falling due within one year	10	(6,143)		(4,440)	
Net current assets			60,284		80,597
Total assets less current liabilities			67,368		80,597
Income funds					
Unrestricted funds			67,368		80,597
			67,368		80,597

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 March 2017. No member of the company has deposited a notice, pursuant to section 476, requiring an audit of these accounts.

The directors acknowledge their responsibilities for ensuring that the company keeps accounting records which comply with section 386 of the Act and for preparing accounts which give a true and fair view of the state of affairs of the company as at the end of the financial year and of its incoming resources and application of resources, including its income and expenditure, for the 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 accounts, so far as applicable to the company.

These accounts have been prepared in accordance with the special provisions relating to small companies within Part 15 of the Companies Act 2006.

The accounts were approved by the Board on 22 December 2017

A Flint
Trustee



Company Registration No. 5407899

THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

NOTES TO THE ACCOUNTS

FOR THE YEAR ENDED 31 MARCH 2017

1 Accounting policies

1.1 Basis of preparation

The accounts have been prepared under the historical cost convention.

The accounts have been prepared in accordance with applicable accounting standards, the Statement of Recommended Practice, "Accounting and Reporting by Charities", issued in March 2005 and the Companies Act 2006.

1.2 Tangible fixed assets and depreciation

Tangible fixed assets are stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost less estimated residual value of each asset over its expected useful life, as follows:

1.3 Stock

Stock is valued at the lower of cost and net realisable value.

2 Donations and legacies

	2017 £	2016 £
Donations and gifts	<u>29,178</u>	<u>20,830</u>

3 Incoming resources from charitable activities

	2017 £	2016 £
Fundraising events	9,512	35,911
Charity Shop takings	249,707	176,007
Conference and Gala Ball	31,997	824
	<u>291,216</u>	<u>212,742</u>

4 Investment income

	2017 £	2016 £
Interest receivable	<u>13</u>	<u>19</u>

THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

NOTES TO THE ACCOUNTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2017

5 Total resources expended

	2017 £	2016 £
Costs of generating funds		
Costs of generating donations and legacies	4,866	-
Charitable activities		
Fundraising events		
Conference and charity events	63,185	-
Research and Family Support		
Activities undertaken directly	36,904	3,799
Charity Shop running costs and goods for resale		
Activities undertaken directly	208,165	151,749
Support costs	26,879	24,145
Governance costs	4,379	5,481
	<u>344,378</u>	<u>185,174</u>

Governance costs includes payments to the accountants of £2,500 (2016 : £2,220) for independent examination.

6 Trustees

None of the trustees (or any persons connected with them) received any remuneration during the year.

THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

NOTES TO THE ACCOUNTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2017

7 Employees

Number of employees

The average monthly number of employees during the year was:

	2017 Number	2016 Number
Administration	3	3
Shop Supervisors	2	3
Tea Room Supervisor	1	1
Part- time and summer	13	13
	<u>19</u>	<u>20</u>

Employment costs

	2017 £	2016 £
Wages and salaries	<u>86,190</u>	<u>65,010</u>

In addition to the above paid staff the charity benefited from the help of around 30 unpaid volunteers during the year.

There were no employees whose annual remuneration was £60,000 or more.

8 Tangible fixed assets

	Fixtures, fittings & equipment £
Cost	
At 1 April 2016	-
Additions	9,446
At 31 March 2017	<u>9,446</u>
Depreciation	
At 1 April 2016	-
Charge for the year	2,362
At 31 March 2017	<u>2,362</u>
Net book value	
At 31 March 2017	<u><u>7,084</u></u>

THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

NOTES TO THE ACCOUNTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2017

9	Debtors	2017 £	2016 £
	Other debtors	1,611	1,611
	Prepayments and accrued income	-	5,540
		<u>1,611</u>	<u>7,151</u>

10	Creditors: amounts falling due within one year	2017 £	2016 £
	Taxes and social security costs	929	-
	Accruals	5,214	4,440
		<u>6,143</u>	<u>4,440</u>