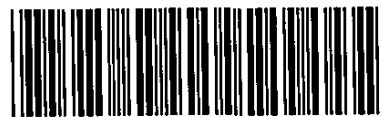


Charity Registration No. 1114367

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 2013

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

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees

A C Flint
L C Flint
B Jefferies
J Jefferies
C M W Sparks
Dr S Heales

Secretary

L C Flint

Charity number

1114367

Company number

5407899

Principal address

Pippins
29 East Parkside
Great Park
Worlingham
Surrey
CR6 9PY

Registered office

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

Independent examiner

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

Bankers

Barclays Bank
Barclays Bank plc
1 North End
Croydon
CR9 1SX

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

TRUSTEES' REPORT

FOR THE YEAR ENDED 31 MARCH 2013

The trustees presents it's report and accounts for the year ended 31 March 2013

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

A C Flint
L C Flint
B Jefferies
J Jefferies
C M W Sparks
Dr 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 aspects of the Charity's business.

The AADC Research Trust is made up of six Trustees who 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 Trust's 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 2013

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 have 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 given to funding and supporting research and projects by other reputable charities where there may be benefits to sufferers of AADC deficiency

Achievements and performance

Although a difficult fundraising year it has been an extremely important year for AADC Research As we embarked on 2012/2013 and following a highly successful International Conference in 2011, it was very apparent that a renewed wave of interest in our disease was shared amongst scientists around the world

AADC Gene Therapy, originally designed for Parkinson's disease, became the main topic of interest. With the Trusts approval of a part grant, the regulatory documents were prepared and submitted to the FDA in America for approval of its potential use on AADC deficient children The trial will take place during 2014/15 at the National Institute of Health in Washington and additionally with the help of 3 of the Trusts Medical and Scientific Advisory members a concurrent trial could take place at Great Ormond Street Children's Hospital (GOSH) here in London A meeting with all relevant AADC Medical Professionals, GOSH Regulatory Officers and Trust Personnel is scheduled for April 2014 to discuss The safety of our children is paramount and being extremely vulnerable much more work is still to be carried out during 2013/14 to ensure the selection process and pre and post operative care procedures cover every aspect of their well-being before consideration is given to be part of any trial

This pioneering treatment could set the benchmark for the treatment of all other neurotransmitter diseases in the future

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

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2013

It has been a static year of fundraising and again the continuing economic downturn during this period is making small organisations such as ours difficult to raise the substantial funds required to carry out the research we are instrumental in bringing about. The Trust is involved with many state of the art scientific research methods which hold potential for many other neurological diseases. Its lack of funds is severely hampering research opportunities and we are 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 Charity invested in an upgrade of its website giving it a fresh and up to date appearance.

Towards the end of the financial year 2012/2013 the Trustees took the decision to relocate its shop to larger premises which is scheduled to re-open in June 2013. A permanent shop/location is now essential to further advance awareness of this and other neurotransmitter diseases particularly as medical and scientific interest grows and more and more children are being correctly diagnosed. The newer 100ft, single storey premises have a guaranteed larger footfall and will include a Charity Boutique, Tea Room and a small office. Additionally it will be ideally suited to be a safer place for our aging volunteers to work and will also be suitable for us to hold meetings to explore alternative methods of fundraising as well as provide in-house fundraising opportunities, particularly for children such as Santa's Grotto. The Premises is located within the vicinity of 5 local schools of varying ages and it is hoped we will employ the help of students to assist with fundraising & volunteering activities.

In the coming years we will be following 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 USA and UK 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 diagnostic procedures will help as costs will be greatly reduced, tests less invasive and referrals to specialist centres more informed
- Consider a project looking at whether symptoms varying from child to child are related to specific AADC mutations
- Consider a future 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 carers (parents and siblings) to see if they are symptomatic as some families report.

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

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

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2013

Financial review

Expenses are kept to a minimum and the Chanty, 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 Chanty 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.

A second account is held at an alternative bank and should our day to day bank account (as detailed above) collectively exceed £35,000 the Trust will direct its funds to here in order to protect itself from the insecurities of the financial institutions.

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

L C Flint
Trustee
Dated



29 JANUARY 2014

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 2013, which are set out on pages 6 to 10

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

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 Limited

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

Dated 29 JANUARY 2014

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

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2013

	Notes	2013 £	2012 £
<u>Incoming resources from generated funds</u>			
Donations and legacies	2	19,902	21,363
Investment income	3	15	18
		<u>19,917</u>	<u>21,381</u>
Incoming resources from charitable activities	4	47,850	21,233
		<u>67,767</u>	<u>42,614</u>
Total incoming resources			
<u>Resources expended</u>	5		
Charitable activities			
Fundraising events		43,801	41,605
Family Support		10,301	8,656
Charity Shop running costs and goods for resale		4,077	7,222
		<u>2,082</u>	<u>1,728</u>
Governance costs			
Total resources expended		<u>60,261</u>	<u>59,211</u>
Net income/(expenditure) for the year/ Net movement in funds		7,506	(16,597)
Fund balances at 1 April 2012		<u>34,884</u>	51,481
Fund balances at 31 March 2013		<u><u>42,390</u></u>	<u><u>34,884</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 2013

	Notes	2013 £	£	2012 £	£
Current assets					
Stocks		3,801		4,752	
Debtors	8	3,320		3,320	
Investments		420		-	
Cash at bank and in hand		37,574		28,540	
		<u>45,115</u>		<u>36,612</u>	
Creditors: amounts falling due within one year	9	<u>(2,725)</u>		<u>(1,728)</u>	
Total assets less current liabilities			<u>42,390</u>		<u>34,884</u>
Income funds					
Unrestricted funds			<u>42,390</u>		<u>34,884</u>
			<u>42,390</u>		<u>34,884</u>


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 2013. 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 29 JANUARY 2014


A C Flint
Trustee


L C Flint
Trustee

Company Registration No. 5407899

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

NOTES TO THE ACCOUNTS

FOR THE YEAR ENDED 31 MARCH 2013

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 Investments

1.3 Stock

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

2 Donations and legacies

	2013 £	2012 £
Donations and gifts	<u>19,902</u>	<u>21,363</u>

3 Investment income

	2013 £	2012 £
Interest receivable	<u>15</u>	<u>18</u>

4 Incoming resources from charitable activities

	2013 £	2012 £
Fundraising events	3,477	5,774
Charity Shop takings	29,079	15,459
Online Sales	15,294	-
	<u>47,850</u>	<u>21,233</u>

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

NOTES TO THE ACCOUNTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2013

5	Total resources expended	costs £	2013 £	2012 £
	Charitable activities			
	Fundraising events			
	Activities undertaken directly	-	43,801	41,605
	Research			
	Family Support			
	Activities undertaken directly	-	10,301	8,656
	Charity Shop running costs and goods for resale			
	Activities undertaken directly	-	4,077	-
	Governance costs	5,813	2,082	1,728
		<u>5,562</u>	<u>60,261</u>	<u>59,211</u>

Governance costs includes payments to the auditors of £2,082 (2012 - £1,728) for audit fees

6 Trustees

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

7 Employees

Number of employees

The average monthly number of employees during the year was

	2013 Number	2012 Number
Administration	<u>1</u>	<u>-</u>

Employment costs

	2013 £	2012 £
Wages and salaries	<u>5,562</u>	<u>-</u>

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

8	Debtors	2013 £	2012 £
	Other debtors	<u>3,320</u>	<u>3,320</u>

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

NOTES TO THE ACCOUNTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2013

9	Creditors: amounts falling due within one year	2013 £	2012 £
		997	-
	Wages & Salaries Control	1,728	1,728
	Accruals		
		<u>2,725</u>	<u>1,728</u>