

# THE AADC RESEARCH TRUST

England & Wales · Charity number 1114367

## Details

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Other names	AADC
Status	Registered
Legal form	Charitable company
Company number	<a href="#">05407899</a>
Registered	2006-05-24
Register	<a href="#">View on the Charity Commission register</a>

## Contact

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Address	Pineacre Southfields Road Woldingham Caterham Surrey CR3 7BG
Phone	07778 356533
Email	<a href="mailto:enquiries@aadcresearch.org">enquiries@aadcresearch.org</a>
Website	<a href="http://www.aadcresearch.co.uk">www.aadcresearch.co.uk</a>

## Activities

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**Objects:** (A) THE RELIEF OF SICKNESS OF PEOPLE WITH AROMATIC AMINO-ACID DECARBOXYLASE (AADC) DEFICIENCY AND THEIR PARENTS AND CARERS.(B) TO PROMOTE MEDICAL RESEARCH INTO AROMATIC AMINO-ACID DECARBOXYLASE (AADC) DEFICIENCY AND THE PUBLICATION OF THE USEFUL RESULTS OF SUCH RESEARCH FOR THE BENEFIT OF THE PUBLIC.(C) TO ADVANCE THE EDUCATION OF THE PUBLIC IN AROMATIC AMINO-ACID DECARBOXYLASE (AADC) DEFICIENCY.

**Activities:** Promoting awareness and funding research into AADC. The trust also offers support to AADC affected families.

## Classification

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- **How:** Makes Grants To Individuals, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** People With Disabilities

## Geography

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- Throughout England And Wales

## Finances

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Period end	Income	Expenditure	Assets	Employees
2025-03-31	£4,097	£10,576	-	-
2024-03-31	£6,251	£38,897	-	-
2023-03-31	£6,883	£62,624	-	-
2022-03-31	£26,652	£50,978	-	-
2021-03-31	£43,124	£76,605	-	-

## Trustees

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Name	Role	Appointed
ANTHONY CHARLES FLINT		2006-05-24
BRIAN ANDREW JEFFERIES		2006-05-24
JACQUELINE JEFFERIES		2006-05-24
LISA CHERIE FLINT		2006-05-24
PROFESSOR SIMON JAMES ROBERT HEALES		2006-05-24

**THE AADC RESEARCH TRUST**

England & Wales - Charity number 1114367

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# Accounts

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Charity Registration No. 1114367

Company Registration No. 5407899 (England and Wales)

**THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))**  
**ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2022**

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

## LEGAL AND ADMINISTRATIVE INFORMATION

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<b>Trustees</b>	A Flint L Flint B Jefferies J Jefferies S Heales
<b>Secretary</b>	L Flint
<b>Charity number</b>	1114367
<b>Company number</b>	5407899
<b>Registered office</b>	Airport House Suite 43-45 Purley Way Croydon Surrey CR0 0XZ
<b>Independent examiner</b>	Ledger Sparks Ltd Airport House Suite 43-45 Purley Way Croydon Surrey CR0 0XZ
<b>Bankers</b>	Barclays Bank Barclays Bank Plc 1 North End Croydon Surrey CR91SX

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

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

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)

### FOR THE YEAR ENDED 31 MARCH 2022

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The trustees present their report and financial statements for the year ended 31 March 2022.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's [governing document], the Companies Act 2006 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 and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2016)

#### **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 trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.

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**

The year 2021 to 2022 was a challenge for the charity as it began to slowly recover from the impact of the previous year due to the unprecedented circumstances dictated by the Covid-19 pandemic. With the loss of many volunteers fundraising capacity remained diminished to previous years, however we did see an increase in events such as ToughMudder, Manchester Marathon, and the Race to the Stones, which all had entrées representing the charity.

In May 2021 we launched our annual 'Teddy Wears Blue for AADCd Awareness Week'. This year as many were still wary of mass gatherings, our families raised funds via Facebook Donations. In keeping with our mission to raise awareness we focused our attention on our families as we were acutely aware of the enormous toll that isolation and restrictions had taken on them in the previous year. We endeavoured to continue providing ongoing support for our community via online platforms such as social media and Zoom. As part of our awareness week the Trust, and with the help of volunteers, facilitated five AADCd Family Workshops online.

Each workshop was led by an AADCd medical expert, covering different topics relating to the disease. Workshop 1 was presented by Professor Bankiewicz (Poland) and Dr Pearson (USA); AAV2-hAADC Gene Therapy in Poland/USA. Workshop 2 was presented by Professor Wang-Tso Lee (Taiwan) Families were shown presentations and provided with the opportunity to ask the experts questions/advice at the end of the sessions. These were exceptionally well attended and hugely successful. As we are a multi-national community the Trust felt it important to make the workshops accessible to a wider audience and translated all five into several languages. These videos and their corresponding transcripts were made available on the Charity website.

As restrictions lifted the charity wanted to celebrate the ability to come together again with its volunteers, trustees and AADCd families. In the summer of 2021, we held a meeting for (past) volunteers and our trustees to thank them for their contribution to the survival of the charity and the enormous help they provided to ensure we continued to support our AADCd community. It was also an opportunity to discuss the charities objectives post pandemic. In December 2021 we organised a get together of (past) volunteers and AADCd families which was a huge success and enjoyed by all. Throughout the months of December 2021 – January 2022 the Trust also completed several audits of stock with the help of volunteers.

The #oneRAREstep campaign continued to provide our community access to gene therapy and the lifting of restrictions meant that surgeries could begin again, with more AADCd children receiving this life changing treatment.

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

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

**FOR THE YEAR ENDED 31 MARCH 2022**

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As part of the campaigns scope to provide critical post gene therapy rehabilitation, the Trust supported various forms of follow up therapies such as physio, speech and language, swallowing, and necessary equipment to provide families with the means to take full advantage of the newly developed motor skills that gene therapy unlocks. The Trust has always advocated for a robust after care programme to observe these children on their journey. We believe this is vital to not only monitor progress and efficacy, but also to ensure each child is given the best opportunity to benefit from the treatments impact.

In September 2021, the trust was asked by the European Medical Association (EMA) to participate in approval process for the application by PTC Therapeutics to grant licensing of Eladocagene exuparvovec/Upstaza (a gene therapy drug for the treatment of AADCd) for use within the EU. In December the Trust made a submission which provided critical insight into the drug's potential, based on trial data and our intimate relationship with those who took part. The Trust highlighted areas of concern and made recommendations for the committee to consider when coming to a decision. We are delighted to report that this innovative treatment was approved by the EMA and is yet another step forward in our search for a cure for this devastating disease.

The same Pharmaceutical company, PTC, also made an application for marketing license for eladocagene exuparvovec to the National Institute of Care and Excellence (NICE) in the UK. Again, we were asked to participate in the approval process. The role is key as it ensures the patient voice is heard and provides critical insight of the disease and treatment impact. Over several months the Trust attended and contributed to many meetings with the NICE team and other committee members, we have made several in-depth submissions based on patient interviews and surveys and raised key concerns that have been successfully taken on board, such as the inclusion of Oculogyric Crises (OGCs) as a vital outcomes measure, the need for further long-term data, and the need for long term follow up of gene therapy patients to monitor efficacy. We now eagerly await in anticipation of a positive approval by NICE, thus providing future UK AADCd patients the opportunity to receive this treatment here at home.

The year saw the charity begin to gain ground again after the struggles faced during the pandemic. The Trust continued its support of the AADCd community, its contribution to critical disease research, its collaborative endeavours to create new opportunities and pioneering treatments and maintained its position as the leader of advocacy for AADCd children and their families worldwide.

### **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; two current accounts and one step saver account.

1. The Current Accounts for all funds are kept to a £2,500 minimum.
2. 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.
3. Restricted funds are maintained in a separate bank account.

It is the policy of the trust that unrestricted funds which have not been designated for a specific use should be maintained at a reasonable level to maintain the charity's required expenditure.

### **Structure, governance and management**

The charity 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 memorandums and articles which established the objects and powers of the charitable company and is governed under its articles of association.

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

## **TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)**

### **FOR THE YEAR ENDED 31 MARCH 2022**

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The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements 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 five 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 Charity continues to work with its Medical & Scientific Advisory Members which includes atleast 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.

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

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

*FOR THE YEAR ENDED 31 MARCH 2022*

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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.

### **Statement of trustees' responsibilities**

The trustees, who are also the directors of The AADC Research Trust (formerly PND Association (UK)) for the purpose of company law, are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company Law 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, including the income and expenditure, of the charitable company for that year.

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;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping adequate 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 Companies Act 2006. 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.

On behalf of the board of trustees

**L Flint**

Trustee

Dated: 20 December 2022

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

## INDEPENDENT EXAMINER'S REPORT

### TO THE TRUSTEES OF THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

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I report to the trustees on my examination of the financial statements of The AADC Research Trust (formerly PND Association (UK)) (the charity) for the year ended 31 March 2022 which comprises the financial activities, the Balance sheet and related notes.

#### **Responsibilities and basis of report**

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

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

An independent examination does not involve gathering all the evidence that would be required in an audit and consequently does not cover all the matters that an auditor considers in giving their opinion on the financial statements. The planning and conduct of an audit goes beyond the limited assurance that an independent examination can provide. Consequently, I express no opinion as to whether the financial statements present a 'true and fair' view and my report is limited to those specific matters set out in the independent examiner's statement.

#### **Independent examiner's statement**

I confirm that I am qualified to undertake the examination because I am a member of ACCA, which is one of the listed bodies.

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 that in any material respect:

- 1 accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements 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 financial statements 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).

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

## **INDEPENDENT EXAMINER'S REPORT (CONTINUED)**

### **TO THE TRUSTEES OF THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))**

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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 financial statements to be reached.

**Annie D'Rozario FCCA**

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

Dated: 20 December 2022

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

## STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2022

	Notes	Unrestricted funds Total 2022 £	Restricted funds £	Total 2022 £	Total 2021 £
<b><u>Income and endowments from:</u></b>					
Donations and legacies	2	19,180	-	19,180	26,004
Investment income	3	2	17	19	167
Other income	4	7,453	-	7,453	16,953
<b>Total income and endowments</b>		<u>26,635</u>	<u>17</u>	<u>26,652</u>	<u>43,124</u>
<b><u>Expenditure on:</u></b>					
Charitable activities	5	45,201	5,777	50,978	76,605
<b>Total resources expended</b>		<u>45,201</u>	<u>5,777</u>	<u>50,978</u>	<u>76,605</u>
<b>Net expenditure for the year/ Net movement in funds</b>		(18,566)	(5,760)	(24,326)	(33,481)
Fund balances at 1 April 2021		<u>26,549</u>	<u>159,617</u>	<u>186,166</u>	<u>219,647</u>
<b>Fund balances at 31 March 2022</b>		<u><u>7,983</u></u>	<u><u>153,857</u></u>	<u><u>161,840</u></u>	<u><u>186,166</u></u>

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

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 2022

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	Notes	2022 £	£	2021 £	£
<b>Fixed assets</b>					
Tangible assets	9		1,963		2,618
<b>Current assets</b>					
Cash at bank and in hand		162,761		219,835	
<b>Creditors: amounts falling due within one year</b>	10	(2,884)		(36,287)	
Net current assets			159,877		183,548
<b>Total assets less current liabilities</b>			161,840		186,166
<b>Income funds</b>					
Restricted funds			153,857		159,617
Unrestricted funds			7,983		26,549
			161,840		186,166

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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 2022. No member of the company has deposited a notice, pursuant to section 476, requiring an audit of these financial statements.

The trustees acknowledge their responsibilities for ensuring that the charity keeps accounting records which comply with section 386 of the Act and for preparing financial statements 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 financial statements, so far as applicable to the company.

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

The financial statements were approved by the Trustees on 20 December 2022

L Flint  
Trustee

Company Registration No. 5407899

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

## NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2022

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### 1 Accounting policies

#### Company information

The AADC Research Trust (formerly PND Association (UK)) is a private company limited by guarantee incorporated in England and Wales. The registered office is Airport House, Suite 43-45, Purley Way, Croydon, Surrey, CR0 0XZ.

#### 1.1 Accounting convention

The financial statements have been prepared in accordance with Companies Act 2006 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 and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2016). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities applying FRS 102 Update Bulletin 1 not to prepare a Statement of Cash Flows.

The accounts have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a true and fair view. This departure has involved following the Statement of Recommended Practice for charities applying FRS 102 rather than the version of the Statement of Recommended Practice which is referred to in the Regulations but which has since been withdrawn.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The accounts have been prepared on the historical cost convention. The principal accounting policies adopted are set out below.

#### 1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

#### 1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

#### 1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

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

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

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### 1 Accounting policies

(Continued)

Turnover is measured at the fair value of the consideration received or receivable and represents amounts receivable for goods and services provided in the normal course of business, net of discounts, and other sales related taxes.

#### 1.5 Resources expended

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party. Expenditure is classified by activity. The costs of each activity are made up of total direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use.

Support costs are those costs incurred directly in support of expenditure on the objects of the company. Governance costs are those incurred in connection with administration of the company and compliance with constitutional and statutory requirements.

Charitable activities and Governance costs are costs incurred on the charity's operations, including support costs and costs relating to the governance of the academy trust apportioned to charitable activities.

#### 1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures, fittings & equipment	25% Reducing Balance Method
Computers	25% Reducing Balance Method

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in net income/(expenditure) for the year.

#### 1.7 Financial instruments

The Charity only enters into basic financial instrument transactions that result in the recognition of financial assets and liabilities such as trade and other debtors and creditors, loans from banks and other third parties, loans to related parties and investments in non-puttable ordinary shares.

#### 1.8 Pensions

##### Defined contribution pension plan

The company operates a defined contribution plan for its employees. A defined contribution plan is a pension plan under which the Company pays fixed contributions into a separate entity. Once the contributions have been paid the company has no further payment obligations.

The contributions are recognised as an expense in the statement of comprehensive income when they fall due. Amounts not paid are shown in accruals as a liability in the Balance sheet. The assets of the plan are held separately from the Company in independently administered funds.

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

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

### 1 Accounting policies (Continued)

#### 1.9 Fund Accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the charity and which have not been designated for any other purposes. Investment income, gains and losses are also allocated to unrestricted funds.

#### 1.10 Government Grants

Government grants are recognised at the fair value of the asset received or receivable when there is reasonable assurance that the charity will comply with conditions attaching to them and the grants will be received using the accrual model.

### 2 Donations and legacies

	<b>Total 2022 £</b>	<b>Total 2021 £</b>
Donations and gifts	19,180	26,004

### 3 Investments

	<b>Unrestricted funds £</b>	<b>Restricted funds £</b>	<b>Total 2022 £</b>	<b>Total 2021 £</b>
Interest receivable	2	17	19	167

### 4 Other income

	<b>Unrestricted funds 2022 £</b>	<b>Total 2021 £</b>
Other income	7,453	16,953

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

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

### 5 Charitable activities

	Charitable activities	Activities undertaken directly	Total	Total
	2022	2022	2022	2021
	£	£	£	£
Charity events and merchandise	1,873	-	1,873	-
Research & family support expenditure	-	-	-	4,668
Restricted Funds Charitable Expenditure - One Rare Step	5,777		5,777	32,778
Share of support costs (see note 6)	-	40,266	40,266	36,004
Share of governance costs (see note 6)	-	3,062	3,062	3,155
	<u>7,650</u>	<u>43,328</u>	<u>50,978</u>	<u>76,605</u>
<b>Analysis by fund</b>				
Unrestricted funds	1,873	43,328	45,201	43,827
Restricted funds	5,777	-	5,777	32,778
	<u>7,650</u>	<u>43,328</u>	<u>50,978</u>	<u>76,605</u>

### 6 Support costs

	Support costs	Governance costs	2022	2021
	£	£	£	£
Staff wages and salaries	21,237	-	21,237	21,088
Rent	8,760	-	8,760	7,708
Computer & website costs	6,973	-	6,973	1,992
Subscriptions	1,698	-	1,698	1,382
Postage and stationery	104	-	104	171
Depreciation	654	-	654	872
Rates	205	-	205	637
Insurance	577	-	577	575
Bank charges	58	-	58	353
Donation expense	-	-	-	961
Costs of generating funds	-	-	-	265
Accountancy	-	3,062	3,062	3,155
	<u>40,266</u>	<u>3,062</u>	<u>43,328</u>	<u>39,159</u>

### 7 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 FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2022

#### 8 Employees

##### Number of employees

The average monthly number of employees during the year was:

	2022 Number	2021 Number
Administration	1	1

In addition to the above paid staff the charity benefited from the help of at least 10 unpaid volunteers during the year.

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

#### 9 Tangible fixed assets

	Fixtures, fittings & equipment £	Computers £	Total £
<b>Cost</b>			
At 1 April 2021	1,966	3,783	5,749
At 31 March 2022	1,966	3,783	5,749
<b>Depreciation and impairment</b>			
At 1 April 2021	1,075	2,056	3,131
Depreciation charged in the year	223	432	655
At 31 March 2022	1,298	2,488	3,786
<b>Carrying amount</b>			
At 31 March 2022	668	1,295	1,963
At 31 March 2021	891	1,727	2,618

#### 10 Creditors: amounts falling due within one year

	2022 £	2021 £
Other creditors	-	33,432
Accruals and deferred income	2,884	2,855
	2,884	36,287

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

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

### 11 Analysis of net assets between funds

	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £	Total 2021 £
Fund balances at 31 March 2022 are represented by:				
Tangible assets	1,963	-	1,963	2,618
Current assets/(liabilities)	6,020	153,857	159,877	183,548
	<u>7,983</u>	<u>153,857</u>	<u>161,840</u>	<u>186,166</u>

Restricted funds are raised by families for the families to cover costs for Gene Therapy in Poland for their children. The Trust negotiated terms for gene therapy direct with the surgeon and hospital to enable a direct payment solution for families. The Families created their own JustGiving fundraising platforms on our main campaign page (<https://www.justgiving.com/campaign/onerarestep>) and all the funds raised from the public have been held by the Trust and have covered costs incurred from Gene Therapy, including travel, accommodation, equipment and surgery/hospital expenses. This meant families would be protected from public scrutiny in how their donations were used and no disputes could be raised direct with the families. Any donations left over, in agreement with the families, are to be allocated by the Trust towards other children's pages who are struggling to raise the full amount.

### 12 Event during the reporting period

The Coronavirus (COVID-19) has emerged globally resulting in a significant impact worldwide and the UK government continued to impose restrictions. As a result some charitable operations have been restricted, however the charity continues to operate using alternative methods and remote working. Hence financial statements do not include any adjustments that might result from the outcome of this uncertainty. The trustees are continuing to monitor, assess and act to the current changing environment in order to position the charity to ensure its future success.

### 13 Related party transactions

There were no disclosable related party transactions during the year (2021 - none).

### 14 Cash generated from operations

	2022 £	2021 £
Deficit for the year	(24,326)	(33,481)
Adjustments for:		
Investment income recognised in statement of financial activities	(19)	(167)
Depreciation and impairment of tangible fixed assets	654	872
Movements in working capital:		
(Decrease)/increase in creditors	(33,403)	31,753
<b>Cash absorbed by operations</b>	<u>(57,094)</u>	<u>(1,023)</u>

**THE AADC RESEARCH TRUST**

England & Wales - Charity number 1114367

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# Accounts

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Charity Registration No. 1114367

Company Registration No. 5407899 (England and Wales)

**THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))**  
**ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2021**

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

## LEGAL AND ADMINISTRATIVE INFORMATION

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<b>Trustees</b>	A Flint L Flint B Jefferies J Jefferies S Heales
<b>Secretary</b>	Mrs L C Flint
<b>Charity number</b>	1114367
<b>Company number</b>	5407899
<b>Registered office</b>	Airport House Suite 43-45 Purley Way Croydon Surrey CR0 0XZ
<b>Independent examiner</b>	Ledger Sparks Audit LLP Airport House Suite 43-45 Purley Way Croydon Surrey CR0 0XZ
<b>Bankers</b>	Barclays Bank Barclays Bank Plc 1 North End Croydon Surrey CR91SX

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

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

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)

### FOR THE YEAR ENDED 31 MARCH 2021

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The trustees present their report and financial statements for the year ended 31 March 2021.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's [governing document], the Companies Act 2006 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 and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2016)

#### **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 trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.

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**

The year 2020 to 2021 has been a challenging one for the Trust. The unprecedented circumstances dictated by the Covid-19 pandemic had a huge impact on the charity, particularly in terms of fundraising capacity and the mobility of both volunteers and staff. The consequences of lockdowns and the furloughing of our paid staff member, saw an acute decline in fundraising incomes and charity activity.

In light of this, the Trust turned its attention to providing ongoing support for its community during an extremely worrying time, that not only affected access to care, therapies, and treatments, but also the emotional health of our AADCd families. We quickly reviewed our priorities to focus on communication using virtual platforms to facilitate support groups (*Coffee Shop Catch Ups*) where families could raise their concerns, for example the safety of Covid vaccinations for AADCd children. The Trust also facilitated virtual meetings with medical experts, where families could discuss Gene Therapy concerns in relation to the current pandemic crisis.

AAV2-hAADC Gene Therapy Treatment, had to be postponed due to the extremely difficult circumstances posed by the threat of Covid. However, Professor Bankiewicz and his incredible team went to extraordinary lengths to meet that challenge and in September 2020 two children received Gene Therapy in Poland and later, in October 2020, another child received it in USA.

The final stage of The AADC Somatic Rehabilitation Therapy Project (launched in 2019 in collaboration with Spiral Praxis) was due to take place mid-2020, however in March Covid-19 struck. Travel restrictions and the vulnerability of the participants meant that we were unable to complete this stage. The Trust re-evaluated its position and determined that the safest option would be to facilitate virtual online group and individual therapy sessions. These were held in August, September, and October 2020. It was established that they were beneficial in educating parents/carers and progress was noted in the children, but this method was not entirely conducive, to the creation of a filmed documentary.

The Trust held discussions with Spiral Praxis, and in March 2021 it was mutually agreed that unfortunately the project had to prematurely conclude, due to the unforeseen circumstances of the pandemic. Funds raised for this project (via the Campaign) are currently held by The Trust in a dedicated account. In agreement with the participating families, The Trust will consider whether to reinvest the funds in further therapeutic projects, repurpose them to those families still trying to reach target on the Campaign, or grant them to the relevant participants for purposes pertinent to the original concept of rehabilitation.

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

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

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We have seen a sharp increase in children receiving a positive diagnosis during the period 2020/2021. In parallel, however, we have lost a further three children to this dreadful disease. These events reinforce the need to push forward with raising awareness and driving critical disease research.

To this effect, in April our Founder and Managing Director, Lisa Flint, was asked to participate in a study by Professor Thomas Opladen (Germany) researching VLA measurement in urine. In May 2020 the Trust was asked to contribute to the publication in the JMD: *AADC deficiency from infancy to adulthood: Symptoms and developmental outcome in an international cohort of 63 patients*. A retrospective study of the biggest cohort of AADCd sufferers around the world. In July 2020 Lisa was asked to submit an entry in the publication: *PND 'Inherited Disorders of Biogenic Amines: A Practical Guide (Chapter 11 Resources for professionals, patients and their families)* by Professor Nenad Blau. In September 2020 the Trust funded a research initiative by Dr Roser Pons (Greece). This research was centred on understanding and creating a symptom scale (dystonia measurement).

In summary, due to the extreme difficulties faced during the period of 2020/2021, the Trust had an unusually quiet year. However, we have continued to support and connect our community by utilising new, pandemic appropriate, methods. Three children received AAV2-AADC Gene Therapy. The Somatic Therapy Project showed substantial benefits and exciting results. Although we were unable to produce a conclusive documentary, there is great potential for further AADCd children to gain from the outcomes of this project. We have continued to support and encourage vital disease research and eagerly await the outcomes, thanks to the continued interest from the international medical community.

#### 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; two current accounts and one step saver account.

1. The Current Accounts for all funds are kept to a £2,500 minimum.
2. 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.
3. Restricted funds are maintained in a separate bank account.

It is the policy of the trust that unrestricted funds which have not been designated for a specific use should be maintained at a reasonable level to maintain the charity's required expenditure.

#### Structure, governance and management

The charity 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 and up to the date of signature of the financial statements were:

A Flint  
L Flint  
B Jefferies  
J Jefferies  
S Heales

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

## **TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)**

### ***FOR THE YEAR ENDED 31 MARCH 2021***

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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 five 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 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.

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

## TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

**FOR THE YEAR ENDED 31 MARCH 2021**

---

### **Statement of trustees' responsibilities**

The trustees, who are also the directors of The AADC Research Trust (formerly PND Association (UK)) for the purpose of company law, are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company Law 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, including the income and expenditure, of the charitable company for that year.

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;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping adequate 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 Companies Act 2006. 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.

On behalf of the board of trustees

.....  
**L Flint**  
Trustee  
Dated: .....

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

## INDEPENDENT EXAMINER'S REPORT

### TO THE TRUSTEES OF THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

---

I report to the trustees on my examination of the financial statements of The AADC Research Trust (formerly PND Association (UK)) (the charity) for the year ended 31 March 2021 which comprises the financial activities, the Balance sheet and related notes.

#### **Responsibilities and basis of report**

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

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

An independent examination does not involve gathering all the evidence that would be required in an audit and consequently does not cover all the matters that an auditor considers in giving their opinion on the financial statements. The planning and conduct of an audit goes beyond the limited assurance that an independent examination can provide. Consequently, I express no opinion as to whether the financial statements present a 'true and fair' view and my report is limited to those specific matters set out in the independent examiner's statement.

#### **Independent examiner's statement**

I confirm that I am qualified to undertake the examination because I am a member of ICAEW, which is one of the listed bodies.

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 that in any material respect:

- 1 accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements 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 financial statements 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).

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

## INDEPENDENT EXAMINER'S REPORT (CONTINUED)

### TO THE TRUSTEES OF THE AADC RESEARCH TRUST (FORMERLY PND ASSOCIATION (UK))

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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 financial statements to be reached.

**Bobby Gurdep Bhogal FCCA**

Ledger Sparks Audit LLP

Airport House

Suite 43-45

Purley Way

Croydon

Surrey

CR0 0XZ

Dated: .....

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

## STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2021

	Notes	Unrestricted funds Total 2021 £	Restricted funds £	Total 2021 £	Total 2020 £
<b><u>Income and endowments from:</u></b>					
Donations and legacies	2	8,003	18,001	26,004	401,814
Investment income	3	14	153	167	336
Other income	4	16,953	-	16,953	-
<b>Total income and endowments</b>		<b>24,970</b>	<b>18,154</b>	<b>43,124</b>	<b>402,150</b>
<b><u>Expenditure on:</u></b>					
Costs of generating donations and legacies		-	-	-	-
Charitable activities	5	43,827	32,778	76,605	210,076
<b>Total resources expended</b>		<b>43,827</b>	<b>32,778</b>	<b>76,605</b>	<b>210,076</b>
<b>Net (expenditure)/income for the year/ Net movement in funds</b>		<b>(18,857)</b>	<b>(14,624)</b>	<b>(33,481)</b>	<b>192,074</b>
Fund balances at 1 April 2020		45,406	174,241	219,647	27,573
<b>Fund balances at 31 March 2021</b>		<b>26,549</b>	<b>159,617</b>	<b>186,166</b>	<b>219,647</b>

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

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 2021

	Notes	2021 £	£	2020 £	£
<b>Fixed assets</b>					
Tangible assets	9		2,618		3,489
<b>Current assets</b>					
Cash at bank and in hand		219,835		220,692	
<b>Creditors: amounts falling due within one year</b>	10	(36,287)		(4,534)	
Net current assets			183,548		216,158
<b>Total assets less current liabilities</b>			186,166		219,647
<b>Income funds</b>					
Restricted funds			159,617		174,241
Unrestricted funds			26,549		45,406
			186,166		219,647

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 2021. No member of the company has deposited a notice, pursuant to section 476, requiring an audit of these financial statements.

The trustees acknowledge their responsibilities for ensuring that the charity keeps accounting records which comply with section 386 of the Act and for preparing financial statements 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 financial statements, so far as applicable to the company.

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

The financial statements were approved by the Trustees on .....

.....

L Flint  
Trustee

Company Registration No. 5407899

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

## NOTES TO THE FINANCIAL STATEMENTS

**FOR THE YEAR ENDED 31 MARCH 2021**

---

### 1 Accounting policies

#### Company information

The AADC Research Trust (formerly PND Association (UK)) is a private company limited by guarantee incorporated in England and Wales. The registered office is Airport House, Suite 43-45, Purley Way, Croydon, Surrey, CR0 0XZ.

#### 1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's [governing document], the Companies Act 2006 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 and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2016). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities applying FRS 102 Update Bulletin 1 not to prepare a Statement of Cash Flows.

The accounts have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a true and fair view. This departure has involved following the Statement of Recommended Practice for charities applying FRS 102 rather than the version of the Statement of Recommended Practice which is referred to in the Regulations but which has since been withdrawn.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The accounts have been prepared on the historical cost convention. The principal accounting policies adopted are set out below.

#### 1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

#### 1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

#### 1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

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

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

---

### 1 Accounting policies

(Continued)

Turnover is measured at the fair value of the consideration received or receivable and represents amounts receivable for goods and services provided in the normal course of business, net of discounts, and other sales related taxes.

#### 1.5 Resources expended

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party. Expenditure is classified by activity. The costs of each activity are made up of total direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use.

Support costs are those costs incurred directly in support of expenditure on the objects of the company. Governance costs are those incurred in connection with administration of the company and compliance with constitutional and statutory requirements.

Charitable activities and Governance costs are costs incurred on the charity's operations, including support costs and costs relating to the governance of the academy trust apportioned to charitable activities.

#### 1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures, fittings & equipment	25% Reducing Balance Method
Computers	25% Reducing Balance Method

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in net income/(expenditure) for the year.

#### 1.7 Financial instruments

The Charity only enters into basic financial instrument transactions that result in the recognition of financial assets and liabilities such as trade and other debtors and creditors, loans from banks and other third parties, loans to related parties and investments in non-puttable ordinary shares.

#### 1.8 Pensions

##### Defined contribution pension plan

The company operates a defined contribution plan for its employees. A defined contribution plan is a pension plan under which the Company pays fixed contributions into a separate entity. Once the contributions have been paid the company has no further payment obligations.

The contributions are recognised as an expense in the statement of comprehensive income when they fall due. Amounts not paid are shown in accruals as a liability in the Balance sheet. The assets of the plan are held separately from the Company in independently administered funds.

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

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 1 Accounting policies (Continued)

#### 1.9 Fund Accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the charity and which have not been designated for any other purposes. Investment income, gains and losses are also allocated to unrestricted funds.

#### 1.10 Government Grants

Government grants are recognised at the fair value of the asset received or receivable when there is reasonable assurance that the charity will comply with conditions attaching to them and the grants will be received using the accrual model.

### 2 Donations and legacies

	Unrestricted funds £	Restricted funds £	Total 2021 £	Total 2020 £
Donations and gifts	8,003	18,001	26,004	401,814

### 3 Investments

	Unrestricted funds £	Restricted funds £	Total 2021 £	Total 2020 £
Interest receivable	14	153	167	336

### 4 Other income

	Unrestricted funds 2021 £	Total 2020 £
Other income	16,953	-

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

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 5 Charitable activities

	Charitable activities	Activities undertaken directly	Total	Total
	2021	2021	2021	2020
	£	£	£	£
Conference expenditure	-	-	-	1,336
Charity events and merchandise	-	-	-	824
Research & family support expenditure	-	4,668	4,668	6,368
Restricted Funds Charitable Expenditure - One Rare Step	32,778		32,778	156,180
Share of support costs (see note 6)	-	36,004	36,004	42,165
Share of governance costs (see note 6)	-	3,155	3,155	3,203
	<u>32,778</u>	<u>43,827</u>	<u>76,605</u>	<u>210,076</u>
<b>Analysis by fund</b>				
Unrestricted funds	-	43,827	43,827	53,896
Restricted funds	32,778	-	32,778	156,180
	<u>32,778</u>	<u>43,827</u>	<u>76,605</u>	<u>210,076</u>

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

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 6 Support costs

	Support costs	Governance costs	2021	2020
	£	£	£	£
Staff wages and salaries	21,088	-	21,088	21,240
Rent	7,708	-	7,708	10,275
Computer & website costs	1,992	-	1,992	2,062
Subscriptions	1,382	-	1,382	1,280
Donation expense	961	-	961	-
Depreciation	872	-	872	998
Rates	637	-	637	431
Insurance	575	-	575	577
Bank charges	353	-	353	60
Costs of generating funds	265	-	265	26
Postage and stationery	171	-	171	159
Accountancy	-	3,155	3,155	3,203
UF Loss on disposal of tangible fixed assets	-	-	-	3,180
Repairs and maintenance	-	-	-	1,030
Staff training & support costs	-	-	-	570
Advertising expense	-	-	-	244
Sundry expenses	-	-	-	33
	<u>36,004</u>	<u>3,155</u>	<u>39,159</u>	<u>45,368</u>

### 7 Trustees

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

### 8 Employees

#### Number of employees

The average monthly number of employees during the year was:

	2021	2020
	Number	Number
Administration	<u>1</u>	<u>1</u>

In addition to the above paid staff the charity benefited from the help of around 10 unpaid volunteers during the year.

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

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

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

### 9 Tangible fixed assets

	Fixtures, fittings & equipment £	Computers £	Total £
<b>Cost</b>			
At 1 April 2020	1,966	3,783	5,749
At 31 March 2021	1,966	3,783	5,749
<b>Depreciation and impairment</b>			
At 1 April 2020	778	1,481	2,259
Depreciation charged in the year	297	575	872
At 31 March 2021	1,075	2,056	3,131
<b>Carrying amount</b>			
At 31 March 2021	891	1,727	2,618
At 31 March 2020	1,188	2,301	3,489

### 10 Creditors: amounts falling due within one year

	2021 £	2020 £
Other taxation and social security	-	148
Other creditors	33,432	1,153
Accruals and deferred income	2,855	3,233
	36,287	4,534

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

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 11 Analysis of net assets between funds

	Unrestricted funds 2021 £	Restricted funds 2021 £	Total 2021 £	Total 2020 £
Fund balances at 31 March 2021 are represented by:				
Tangible assets	2,618	-	2,618	3,489
Current assets/(liabilities)	23,932	159,616	183,548	216,158
	<u>26,550</u>	<u>159,616</u>	<u>186,166</u>	<u>219,647</u>

Restricted funds are raised by families for the families to cover costs for Gene Therapy in Poland for their children. The Trust negotiated terms for gene therapy direct with the surgeon and hospital to enable a direct payment solution for families. The Families created their own JustGiving fundraising platforms on our main campaign page (<https://www.justgiving.com/campaign/onerarestep>) and all the funds raised from the public have been held by the Trust and have covered costs incurred from Gene Therapy, including travel, accommodation, equipment and surgery/hospital expenses. This meant families would be protected from public scrutiny in how their donations were used and no disputes could be raised direct with the families. Any donations left over, in agreement with the families, are to be allocated by the Trust towards other children's pages who are struggling to raise the full amount. Additionally, the Trust employed the help of a somatic therapist and created a project to rehabilitate children post surgery to enable a 'best outcome' opportunity for children having this new pioneering brain surgery.

### 12 Event during the reporting period

The Coronavirus (COVID-19) has emerged globally resulting in a significant impact worldwide and the UK government continued to impose restrictions in 2021. As a result some charitable operations have been restricted, however the charity continues to operate using alternative methods and remote working. Hence financial statements do not include any adjustments that might result from the outcome of this uncertainty. The trustees are continuing to monitor, assess and act to the current changing environment in order to position the charity to ensure its future success.

### 13 Related party transactions

There were no disclosable related party transactions during the year (2020 - none).

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

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

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14 Cash generated from operations	2021 £	2020 £
(Deficit)/surplus for the year	(33,481)	192,074
Adjustments for:		
Investment income recognised in statement of financial activities	(167)	(336)
Depreciation and impairment of tangible fixed assets	872	997
Loss on disposal of tangible assets	-	3,180
Movements in working capital:		
(Increase)/decrease in debtors	-	100
Increase in creditors	31,753	1,865
<b>Cash (absorbed by)/generated from operations</b>	<u>(1,023)</u>	<u>197,880</u>