Company number: 5174065
Charity number (England & Wales): 1107539
Charity number (Scotland): SC049810

# THE APLASTIC ANAEMIA TRUST

A Company Limited by Guarantee (Registered Charity No. 1107539. England & Wales) (Registered Charity No. SC049810, Scotland)

**REPORT AND FINANCIAL STATEMENTS** 

FOR THE YEAR ENDED

31 MARCH 2020

Leonard Jones & Co Chartered Accountants 1 Printing House Yard London E2 7PR



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# The Aplastic Anaemia Trust (AAT) Bringing Failed Bone Marrow Back to Life

#### **Chairman's Statement**

The financial year 2019/2020 was marked most significantly by the Covid-19 pandemic which started to stir in January and February and showed its devastating effects in the final month of our fiscal year ending on 31 March 2020 and thereafter. The effect on our patient community, many of whom are immune-compromised and —suppressed, could not have been more destabilising and alarming. Our clinical advisors and the patient support group were effective at providing information and helpful communication for AA and related diseases patients. At the time of writing (July 2020), the long-term effects of the pandemic remain unclear, but some sense of order has returned and access to clinical support has improved, if not back to normal levels yet. Special thanks must go to Grazina Berry and so many volunteers who were able to marshal the support and help needed in this harrowing Spring of 2020.

We extend our gratitude to Grazina who has resigned as chief executive of the AAT. Her work has been transformational and she has professionalised the charity and its functions, vastly extending the depth and reach of our services. We wish Grazina the best of luck in her new role and thank her sincerely for what she has done for us in her time here.

We have been very fortunate to identify and appoint a highly capable and experienced new chief executive, Ms Stevie Tyler, as of 1 July. Stevie comes to us with deep and wide-reaching experience in the charity sector and has a successful fundraising track record. She is an Oxford graduate, has spent five years with Macmillan Cancer Support and has worked with leading charities such as the NSPCC, Save the Children and British Heart Foundation as an adviser. We are excited and enormously pleased to have Stevie as our new CEO and ask our supporters to join us in warmly welcoming her to the AAT.

The pandemic has overshadowed almost everything that has happened during the 2019-20 fiscal year. Nonetheless, the AAT continued a programme of modernisation and updating started in 2018-19. Most importantly, the Board of Trustees met in January 2020 to decide on a medium-term strategy, supported and moderated by LEK Consulting, a leading international strategy consulting firm, to whom we owe sincere thanks for their help. The strategy is based on three key pillars:

- We will continue to support patients and their families through our successful Patient Support Group, across social media channels and in-person support.
- The AAT will focus on facilitating research funding to find a cure for aplastic anaemia and related bone marrow failure
  disease, helping clinicians source funding from donors, grant giving trusts and other sources and co-funding this
  research.
- We will establish and promote effective and vocal patients' advocacy at a national level and with key stakeholders in healthcare providers and decision makers.

We have also extended the AAT's national reach by registering with the Scottish charity regulator as well as extending our activities there and in Northern Ireland. This will allow us to take our work and support to all the four nations.

Our new CEO will drive the execution and implementation of this strategy with the full support of the Board of Trustees of the charity. Based on this clear and realistic focus, we are confident that we are able to continue to play a relevant role in improving the quality of life and outcomes for our patient community, despite the challenges thrown at us specifically and at the charity sector generally by the Covid-19 pandemic. Undoubtedly, we continue to face a challenging and difficult operating environment as communicated in my last statement. However, we have a clear sense of purpose, we know there is an enormous need for what we do and we are supported by a fantastic group of volunteers and contributors in achieving our overarching goal: to find a cure for aplastic anaemia.

As ever, we thank our supporters, volunteers, donors and the Trustees for their dedication to the AAT. We appeal to all who support and sustain our efforts to continue and intensify their work to help the charity to fight AA and help those who suffer from the disease. Please support us in our aims in any way you can.

Chair of the Board of Trustees

3 September 2020

(Company number: 5174065) (Charity number: 1107539)

#### TRUSTEES' REPORT (INCORPORATING THE DIRECTORS' REPORT)

The Trustees, who are also Directors for the purposes of the Companies Act 2006, are pleased to present their annual report together with the financial statements for the year ended 31 March 2020.

#### **Our Mission, Vision and Objectives**

The Aplastic Anaemia Trust exists to enable vital research into the causes of aplastic anaemia and other rare bone marrow failures that ultimately leads to the eradication of the diseases, and to support everyone affected by them, so they can lead healthy and fulfilling lives.

Our activity in 2019/20 was geared towards the achievement of the following strategic objectives, to:

- 1. Grow and develop the organisation
- 2. Raise funds for ground-breaking research that enables a better understanding of aplastic anaemia and other rare bone marrow failures and which leads to improved treatments with better outcomes for patients
- 3. Provide everyone affected by aplastic anaemia and allied rare bone marrow failures with the Information, and emotional and practical support they need.

Aplastic anaemia (AA) is a rare and life-threatening form of bone marrow failure. Most cases are acquired. However inherited types of AA are also quite common and can present in adults, not just in children.

In most cases it is an auto-immune disease, whereby the immune system attacks and destroys stem cells. These cells are essential for making all the different type of blood cells within the bone marrow —red cells, white cells and platelets. This results in a deficiency of the blood-making cells and the consequent downstream effects of low blood counts, in all the cell types. As a result, people cannot lead a normal life and, if untreated, will die quickly.

AA affects 2 people per million of population every year in the UK, mostly the young (0-20) and the elderly (60+). This is around 120-150 individuals per year, with a broader impact on the entire family.

#### The challenges we worked hard to address

The challenges aplastic anaemia patients and their families face every day cannot be under-estimated.

They are immune-suppressed and go through a similar treatment and recovery pathway compared to that of blood cancer patients. Treatment is costly, lengthy, exhausting and will affect the whole family. Yet the reality of aplastic anaemia patients' disease journey is starkly different – they are adversely affected by a frequent lack of awareness of the condition, even by healthcare professionals in smaller treatment centres, which can lead to the absence of co-ordinated holistic support that is high-quality and close to home.

Without consistent and reliable information about their treatment options, excellent quality of care, equitable access to treatments and without opportunities to connect with people 'just like them' for peer-to-peer support, AA patients can face extreme anxiety, isolation, stress and health inequalities.

"I've been in the world of aplastic anaemia for 12 years now and I've gone from having 3-4 social circles back then, to having none now. I've not had the best journey since transplant due to complications and side effects of steroids so it's still always happening even now. I'm stuck between the blank ('what the hell are you talking about'?) or the pity ('poor you, you're so brave!') conversations. When people ask me how I am, I've taken to saying "Yeah, fine thanks, same old" and that seems to make most folks happy. It's a very lonely world nowadays".

These complex challenges have been amplified by the Covid-19 crisis that struck the UK in March 2020. Charitable organisations have been particularly hard hit, with individual, community and event fundraising income severely reduced The AAT is no exception. Our charity's priority in the immediate aftermath was to support our vulnerable patients and their family community, the vast majority of whom were advised to shield, in the best way that we could. This meant our new outreach programme turned digital almost overnight, significant effort was invested in securing the best advice from key experts and in distilling vast amounts of frequently changing information and government guidance as best we could for our patient community.

#### TRUSTEES' REPORT (INCORPORATING THE DIRECTORS' REPORT) (continued)

# The challenges we worked hard to address (continued)

The Aplastic Anaemia Trust is the only UK charity working at grassroots, to support every aplastic anaemia sufferer and their loved ones and to help relieve the immense disease burden.

#### AAT's achievements and performance highlights for public benefit in 2019/20

The Board of Trustees confirm they have had regard to the Charity Commission's guidance on public benefit and have complied with their duty under section 4 of the Charities Act 2011 when reviewing the charity's aims and objectives and in implementing current and planning future activities.

In line with the governing document, the Memorandum and Articles of Association, our performance highlights against the Charity's aims for the last year are set out below.

2019/20 was another productive year that built on a strong foundation put in place in 2018/19 and was marked with significant achievements, made possible by the unwavering commitment of the AAT's team, volunteers, our aplastic anaemia community members, generous funders and continued organisational development.

#### 1. PATIENT INFORMATION, OUTREACH AND SUPPORT

"This new energy of organising events is super. How these get-togethers can help so much! Previously it was scary with nowhere and no-one to share your fears with. Well done to the Aplastic Anaemia team, it is better than medicine"

#### Our achievements in 2019/20:

- We developed and piloted a new national aplastic anaemia Support and Outreach Programme, which combined:
  - o Family Information Events bringing together patient communities and key haematology experts across the UK's regions. This programme connected clinicians involved in the treatment of patients with AA and allied rare bone marrow failures with families affected by AA, providing them with an overview of treatments available, any new developments and information on support available
  - Informal local peer-to-peer meetings enabling mutual support and leading to positive psycho-social impact.
- We delivered 12 such events last year, reaching over 300 people.
- A large-scale event was organised working with the Stem Cell Transplantation team at St George's Hospital in London, bringing together stem cell transplantation experts, patients and families across rare bone marrow disease areas, as well as other charities, such as Anthony Nolan and Macmillan Cancer Support. The event focused on holistic care and support that should form part of every patient's experience – alongside medical treatment, focusing on mental wellbeing, exercise, a healthy diet and meaningful activity.

"A very big THANK YOU for arranging a video call in lieu of the Newcastle meeting being changed. It was emotional hearing other people's stories, but also I found it supportive talking to others who really do know how this condition affects us. The call gave me the opportunity to talk and 'meet' for the first time others with this condition."

- Following a successful outreach pilot and having secured charitable grants from a range of generous funders –
  regional grant-giving trusts and foundations, as well as pharma companies, we were able to recruit our first
  Outreach Co-ordinator, who brought to the role remarkable commitment and lived experience of AA.
- We ramped up further our relationship-building work and our information resource distribution across the UK, broadening clinical networks and establishing connections with paediatric and adult treatment centres nationally.
- We proactively encouraged and secured significant patient community growth, increasing the number of new
  members joining our friendly online community by nearly 300 newly diagnosed individuals and their loved ones.
  At year end we had 1650 members in our online support group.

#### TRUSTEES' REPORT (INCORPORATING THE DIRECTORS' REPORT) (continued)

#### 1. PATIENT INFORMATION, OUTREACH AND SUPPORT (continued)

#### Our achievements in 2019/20 (continued):

- Working with the inspiring colleagues in the haematology team at King's College Hospital, London, we developed
  and launched three new practical information guides "How to manage a bleed", "How to ensure good oral
  hygiene when neutropenic" and "How to manage increased urinary urgency and frequency". These guides help
  address frequently occurring problems, to ease anxiety and reduce the need for further clinical intervention.
- Building further on the above productive relationship, we developed and delivered a 2-day Nurse Education
  Programme to the nursing team in Oldham, Manchester, beginning to build up the evidence of need for additional
  focused educational programmes aimed at nursing staff across the UK.

"What a good idea!:) I've had to explain AA to healthcare staff quite a few times before myself! Are you planning on doing this at any other hospitals?"

- Traffic through the AAT's website saw a marked increase compared to last year, with 95,000 page views, 45,000 sessions and 31,000 new users. 67% of those accessing the site were from the UK, 27% from the US, with the remainder from India, Australia, Ireland. The most popular pages were "what is AA", treatment-related resources, blogs and individual fundraising opportunities.
- The website became established not just for easy access to vital information and personal story-sharing, but as a key fundraising platform enabling easy build of individual appeals pages, event promotion, online shopping and individual giving, reaching £76,000 via our online 'Donate' functionality.
- Our bi-monthly e-newsletters continued to be sent to our subscribers bringing to them the latest news and developments, while encouraging them to volunteer, support and engage with our work. Recognising that not everyone is online these days, twice this year, we sent hard copy newsletters to 200 of our community members to ensure they remain connected to the broader AA community.
- Our volunteers continued their role as a real force for good, increasing their ranks to over 50 kind-hearted AAT
  enthusiasts who supported us on specific projects, including the production of vibrant and professional
  information resources, awareness campaigns and delivering our information resources to local hospitals.

#### Coronavirus response, March 2020

- At the end of March 2020 as the UK lockdown started, we transformed peer-to-peer support sessions into weekly
   AAT Connect digital support meetings in England South, England North, Scotland, Wales and Ireland, led by our
   fantastic volunteers.
- Thanks to strong collaborative links with the main treatment centres and our closeness to the needs of the patient community we were able to accelerate the production of specific guidance on dealing with the pandemic for the paediatric and adult AA populations and distributed the information through our website and social media
- We also worked with colleagues at Great Ormond Street and King's College Hospitals to develop and offer to our
  patient communities two interactive webinars to help them understand better what shielding meant and the
  impact of the pandemic on their treatment and recovery.

"Information received from The Aplastic Anaemia Trust has eased my anxiety and helped me make decisions on whether to isolate prior to receiving a government letter. Through this information my son and I, who both live in the same home as my partner with severe AA, decided before lockdown to protect him as much as possible by remaining at home prior to, and throughout lockdown and we will remain in until the risk is lifted to manageable level."

#### MarrowKidz

This vital programme of work to plug the gap in the availability of age-appropriate information and support resources aimed at children, young people and their families living with the AA burden deserves a special mention as the year ends. We were most fortunate to secure a two-year £220,000 grant from the National Lottery Reaching Communities Fund to enable this work.

# TRUSTEES' REPORT (INCORPORATING THE DIRECTORS' REPORT) (continued)

1. PATIENT INFORMATION, OUTREACH AND SUPPORT (continued)

Our achievements in 2019/20 (continued)

MarrowKidz (continued)

A heartfelt thanks goes out to all the National Lottery players and to the funder for fuelling our work in this area!

Excellent progress was made with the project, with a few highlights below:

- Leadership of a professional Programme Manager secured after a robust recruitment process
- Extensive engagement with the young patient and family base nationally to recruit them into ongoing programme
  participation through family engagement events, digital conversations, focus groups and an online survey
- Positive contributions to shaping the resources from paediatric haematology clinicians in London, Leeds, Newcastle, Birmingham and Cambridge
- The mapping of informative factsheets, advice resources and guides across the disease diagnosis, treatment and recovery areas
- Productive digital collaboration started with MindWave, a digital company that designs and develops digital products and services that have a positive impact on people.

"Aplastic Anaemia is one of the most challenging group of illnesses that I treat. It is often hugely overwhelming for children, teenagers and their families to face, and very difficult for their doctors, nurses and many other health professionals to care for these patients. Families find that it is often much harder to find information about and support for their child's illness. Although treatment has improved a great deal over the last 2 decades, there is still less research into the treatment of aplastic anaemia than there is for many other diseases affecting similar numbers of children." Professor Rod Skinner, Newcastle

#### 2. RESEARCH

The AAT is committed to funding three important research projects, to progress treatments of aplastic anaemia and to further the understanding of the disease.

Guided by the AAT's Research Strategy and its 4 objectives, namely, to:

- A. Improve baseline understanding of rare bone marrow failures in child and adult populations.
- B. Improve the understanding of the diseases by molecular/ genetic research into the damaged cells and their environment the pathogenesis of rare bone marrow failures.
- C. Identify risk factors in AA patients that predispose to later MDS/AML.
- D. **Improve treatments**, identifying alternative cures, enabling experimental therapies and ultimately eradicating the diseases, including the personalisation of discovery platforms and treatments for rare BMF syndromes and AA.

..we continued to fund the following projects, governed by our independent Research Advisory Panel, with the collective value of our research investments over the life of the projects, not just the year in question, standing at just under £272,000:

1). Identification and relevance of novel somatic mutations in patients with aplastic anaemia, led by Dr Alex Smith and Professor Judith Marsh, King's College Hospital, London

# Progress headlines:

 A bespoke 291-gene panel was designed and deployed which utilized molecular barcode technology to screen for novel gene mutations to a relatively high sensitivity in AA patients undergoing treatment with the pan-European RACE trail.

# TRUSTEES' REPORT (INCORPORATING THE DIRECTORS' REPORT) (continued)

#### 2. RESEARCH (continued)

#### Progress headlines (continued):

- For the batch of 204 samples (from 104 patients), findings showed that in addition to the 31 genes previously screened in the Cancer Research UK parallel study, a number of other genes in our extended screen panel were associated with candidate mutations.
- Many novel mutational events were seen as patient-specific, "one-off" mutations, when any single gene was
  considered and if potential inherited variants were removed. As this new data set continues to grow, the
  researchers will be able to establish further functional and pathological relevance to any recurrent candidate
  driver-mutations, and link this to treatment. The full release of clinical data will be available after the trial ends,
  hopefully later in 2020.
- 2). Establishment of a paediatric UK bone marrow failure registry and biobank, led by Dr Sujith Samarasinghe, Great Ormond Street Hospital, London

# **Progress headlines:**

- All Children's Cancer and Leukaemia Group (CCLG) paediatric centres approved the collection and sending of blood/marrow from children with AA to the Cell Bank in Manchester. The last centre to do this was in August 2019.
- The registry was set up in York under the Cell Bank Governance structures.
- Data and samples on 20 children were collected. This is about 70% of where we had hoped to be.
- Despite the COVID-19 crisis, biobanking and data registry continued. However, unfortunately, due to a lack of research capacity, the quality-of-life work had to be suspended.

The project will lead to a much better understanding of the causes of AA. It is hoped this will lead to the discovery of novel genes that can result in childhood aplastic anaemia. It is anticipated that data from the The 100,000 Genomes Project on paediatric bone marrow failure (BMF) will be combined with genomic data from banked samples to give us an idea about the spectrum of inherited causes of aplastic anaemia.

3). Production of expanded autologous regulatory T cells to treat patients with refractory aplastic anaemia in a phase I dose study, led by Professor Ghulam Mufti, King's College Hospital, London

In October 2019 we announced this ground-breaking research partnership with LifeArc, a UK-based medical research charity, jointly awarding a £1.15m research grant over 3 years to King's College London and King's College Hospital to investigate the potential of a novel type of "personalised cellular therapy" to reverse aplastic anaemia.

The grant began to fund a clinical trial to investigate the safety and efficacy of using a patient's own T-reg cells to restore the blood-making function of the bone marrow. This follows laboratory-based research from the team of scientists where T-reg cells from a patient's own blood were collected, selected for activity and multiplied. In a test tube, these cells prevented the immune system from attacking the patient's bone marrow stem cells.

"For patients with this ultra-rare disease, we're looking for the first time at a personalised medicine approach where their own immune cells could be used to alter their disease. In AA there is a reduction in the number of T-regs and most of the ones that the AA patients do have are non-functional. We've seen success in the laboratory by selecting and bolstering the number of functional T-reg cells. Now, with funding from LifeArc and the AAT, we can investigate the potential of this approach in treating AA patients who currently have very limited treatment options." Prof Ghulam Mufti

#### Progress headlines:

- The project made a promising start with the recruitment of the research team and project manager.
- The initial drafts of the study protocol were produced.

#### TRUSTEES' REPORT (INCORPORATING THE DIRECTORS' REPORT) (continued)

#### **RESEARCH** (continued)

# Progress headlines (continued):

- Testing of T-reg expansion protocol in the laboratory began with the T-reg expansion culture progressing well at the early stages.
- The pandemic put a pause on all laboratory work, which was set to resume once social-distancing measures were eased later in 2020.

#### 3. AWARENESS RAISING AND STRATEGIC CAPACITY

#### Strategic partnerships:

• We were delighted to initiate The Together for Healthy Marrow Alliance which brought together charities working in the rare bone marrow failure space, such as PNH Support UK, Fanconi Hope, DBA UK and DC Action. It continued to go from strength to strength as the year progressed, with the group expanded to include the Congenital Anaemias Network, Oxford. The alliance began to establish a collaborative platform for sharing organisational learning, research updates and approaches, opportunities for our patient communities to access additional support services, and for us to begin making inroads into professional patient advocacy.

"The Alliance will provide us with a unique collaborative platform for sharing learning, planning and delivering joined solutions to shared problems, representing our community of patients in external networks, including internationally, and projecting our collective voice in the broader rare disease network, such as Genetic Alliance UK."

- During the year, the AAT became a member of the Specialised Healthcare Alliance which exists to seek uniformly
  high levels of care and evidence-based treatments for rare and complex disease patients. For the AAT, this
  membership opened access to valuable network meetings with helpful updates on smoothing access to
  medications for patients with rare conditions, the review of NICE that is currently underway, the national Rare
  Disease UK Strategy refresh and more.
- We built connections with our European and US counterpart organisations.
- Our patient community representative and volunteer Fiona, carried the charity's flag all the way to Amsterdam, to represent the AAT at the annual European Haematology Association Congress:

"I feel the trip to the EHA meeting in Amsterdam was very successful and attendance at such meetings is definitely the way forward for patient advocacy, expanding the AAT's network, understanding new key areas of research, and collaborating with other European AA and rare Bone Marrow Failure groups".

- We joined the national **Children's and Young People's Cancer Coalition**, recognising that some cancer-focused organisations will play a valued part in our young patients' recovery following stem cell transplantation.
- We forged a collaborative partnership with Maggie's Centres across the UK, who kindly agreed to open the doors
  of their beautiful centres to aplastic anaemia patients and to include our patient community with Maggie's mental
  wellbeing support as the Covid-19 crisis struck. We thank Maggie's Centres sincerely for their genuine partnership
  spirit and willingness to support our patient community.

#### Strategic events:

 The AAT exhibited for the first time at the annual British Society for Haematology (BSH) conference in Glasgow in April 2019. Run over three days, the event provided an excellent opportunity to raise the profile of our charity and rare disease area, promote our work, distribute information resources and build new contacts with haematologists and industry partners.

"A diagnosis like AA does not have the protection of being a condition known to almost anyone except patients, families and friends. Providing good clear information and raising awareness is really important."

#### TRUSTEES' REPORT (INCORPORATING THE DIRECTORS' REPORT) (continued)

#### Strategic events (continued):

- Accompanied by our patient community member, we exhibited and raised our profile at the Rare Disease Summit
  in Cambridge that drew together experts, patient-focused organisations and pharma companies. This enabled us
  to not only spread awareness of aplastic anaemia and our work, but also to participate in priority-setting
  workshops, to influence the next iteration of the UK's Rare Disease Strategy.
- The Genetic Alliance UK annual meeting gave us an opportunity to take the stand and speak up about how the rare disease patient voice can be amplified. Through this Alliance some in our patient community were able to participate in the CONCORD study, shining light on the need for co-ordination of care in rare diseases, and to provide input into the next edition of UK's Rare Disease Strategy.
- We began collaborative engagement with **the National Congenital Anomaly and Rare Disease Registration Service** (NCARDRS), Public Health England, to hone in on data available on aplastic anaemia prevalence in England.
- We presented at the International King's Rare Bone Marrow Failure/Aplastic Anaemia meeting, which provided
  us with an opportunity to shed light on the reality of living with AA, broaden our networks and hear hugely
  insightful updates from international experts.
- We participated in the Westminster reception as part of the International Rare Disease Day, discussing aplastic anaemia challenges with MPs, NHS England and Public Health England colleagues as well as other rare disease charities.

"Thank you so much for your contribution at the event. Your presentation was amazing and added considerably to the educational components of the meeting. The discussions between participating centres during the meeting will no doubt flourish collaborations so that we together find new treatment(s) for our patients with rare Bone Marrow Failures and Aplastic Anaemia", Professor Judith Marsh, King's College Hospital, London

#### Awareness campaigns 2019/20:

The primary goals of our awareness campaigns in 2019/20 were to keep our supporters engaged, grow our community and social media following, raise awareness of the cause and funds to fuel our work.

- A new Autumn / Christmas awareness campaign "Bursting to do plenty but running on empty" was launched, during which we shared 12 inspirational blogs, a variety of organisational updates and celebrated the Trustees' week. The reach was excellent with over 45,000 people via social media, attracting nearly 6,000 new visitors to our website (1K more than last year).
- During the campaign we distributed 30 information resource packs across hospitals nationally.
- A successful Spring awareness campaign was run in February and into March (just before Covid-19 struck) "Acutely aware of being incredibly rare". This was our way to mark the International Rare Disease Day and share interesting and rare facts about AA as well as rare moments experienced by people living with AA. Reach via shares on the AAT's open Facebook page hit 66,000 (vs 24,500 during last year's Spring awareness campaign) and increased the number of our Instagram followers.

"I wanted to thank you for running the most wonderful campaign over the last two weeks in the lead up to both the International Rare Disease day and the Aplastic Anaemia Awareness day. It really was excellent from the content, the personal stories, the facts & figures to the graphics - and was wonderful to be able to share it to so many across all the social media sites."

 Two awareness-raising articles featured on the British Society for Haematology website to promote the Aplastic Anaemia Awareness Day on 4 March, and a UK News item in the April edition of the international Rare Revolution Magazine, featuring the AA awareness days delivered to Haematology Nurses at Oldham Care Organisations, in partnership with Simon Slade, Aplastic Anaemia Clinical Nurse Specialist at King's College Hospital.

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#### TRUSTEES' REPORT (INCORPORATING THE DIRECTORS' REPORT) (continued)

#### **Fundraising**

2019/20 saw a marked step forward in community fundraising, with inspiring giving from individuals.

We would like to extend a big Thank You to every individual who raised money for the AAT through your sporting events, community balls, quizzes, pilates classes, cake bakes and sales, knitting and many more wonderful initiatives.

We launched a brand-new community fundraiser "The AATea Party" to mark 4 March, the Aplastic Anaemia Awareness Day and we held with pleasing success our two flagship walks – The Windsor Great Park Walk and the Peak District Walk.

We are enormously grateful to our corporate supporters Armstrong Richardson who continued to help our charity as part of its "Charity of the Year" initiative; and thanks also to ISG and Wedlake Bell who raised funds for us through the annual AAT 300 cycle ride in Spain and the AAT's Annual Quiz.

We were successful in diversifying our income streams, crucial for the AAT's financial sustainability, and secured funds from the following organisations, whom we'd like to thank whole-heartedly and acknowledge:

- Grant-giving Trusts and Foundations
  - o The Britford Bridge Trust
  - o The Barbour Foundation
  - o The Shears Foundation
  - o The Oakdale Trust
  - o The Wesleyan Foundation
  - o The Catherine Cookson Charitable Trust
  - o Birmingham Hospital Saturday Fund
- The National Lottery funds including the Reaching Communities Fund to enable our MarrowKidz initiative, as well as Awards for All England and Awards for All Scotland
- Pharma Companies Jazz Pharmaceuticals, Alexion and Apellis.

#### Trustee development

- Trustees were kept up to date on the broader operating context through quarterly charity and regulatory landscape updates
- A 'Strategy Day' was held in January 2020 to review the charity's achievements and consider the next stage in our prioritising and evolution
- Dr Sujith Samarasinghe, an eminent paediatric haematology consultant from Great Ormond Street Hospital, London joined the Board of Trustees.
- Professor Peter Hillmen, a key national expert in AA and linked disease PNH from St James' Hospital, Leeds, joined
   the Board of Trustees
- The AAT said a fond farewell to the charity's founder Professor Ted Gordon-Smith who kindly agreed to continue his commitment to championing our cause as the AAT's first Patron.

# Looking ahead

The AAT will continue to build on the core activities outlined in the annual report, for the benefit of its patient and family communities.

The Strategy Day held in January 2020 enabled the AAT's Board of Trustees to refine further the organisation's strategic objectives for the future. These will be:

1. Being a grassroots organisation, the AAT will provide every patient and their family affected by AA, with excellent quality information, emotional/ psycho-social and practical support to ease the disease burden, across the UK

THE APLASTIC ANAEMIA TRUST

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#### TRUSTEES' REPORT (INCORPORATING THE DIRECTORS' REPORT) (continued)

#### Looking ahead (continued)

By developing and implementing a comprehensive patient advocacy programme, the AAT will champion AA patients' rights for excellent quality care and treatment nationally raising the profile of the disease and the work of the AAT

3. Through collaborative working, the AAT will act as an enabler of transformative research, focusing on improving patients' quality of life and finding a cure.

The principles underpinning the AAT's strategic objectives will be patient-first ethos, collaborative working and organisational excellence

#### Risk management

The Trustees have a duty to identify, assess and regularly scrutinise the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error. The Trustees have mapped significant risks that may have an adverse effect on the AAT's charitable activities.

The principal risks facing the charity are to do with the pandemic and the management of increased demand for services against a likely sharp fall in community fundraised income.

A robust risk management framework is in place and remains effective in enabling the Trustees to oversee and monitor strategic risks, reviewing progress against specific action plans quarterly.

### **Going Concern**

The Trustees consider there are no material uncertainties about the charitable company's ability to continue as a going concern. The review of the financial position and future plans gives Trustees confidence that the charity remains a going concern for the foreseeable future.

#### **Financial Review**

Unrestricted income for the year totalled £196,488 (2019: £149,477) and expenditure amounted to £262,925 (2019: £255,473) resulting in net expenditure on unrestricted funds for the year of £66,437 (2019: £105,996). In addition, restricted income of £83,320 was receivable (2019: £219,864). Expenditure incurred and charged against restricted income funds amounted to £78,042 (2019: nil), leaving balances on restricted funds totalling £225,142 at 31 March 2020 (2019: £219,864).

At the end of the year the charity had free, unrestricted reserves of £281,397 (2019: reserves of £347,834).

#### **Reserves Policy**

The Trustees have considered the charitable company's position with regard to formulating a reserves policy, aligned with the organisation's strategy moving forward.

Typically, the charitable company:

- Makes time-limited commitments to fund projects, research, staffing costs which are capped either explicitly or by a time-limit to funding an on-going cost.
- Engages in time-limited commitments with regard to operating costs, consisting in the main of direct and indirect wage costs, as far as is possible and reasonable.

# TRUSTEES' REPORT (INCORPORATING THE DIRECTORS' REPORT) (continued)

#### **Reserves Policy (continued)**

Under its reserve policy the charitable company follows the following principles:

- Ensure that it has an operating income reserve equivalent to approximately 12 months of operational costs of the
  charity plus a reasonable amount of investment funds to draw upon, in line with the strategy, to be agreed by the
  Trustees.
- Ensure that the charitable company retains reasonable reserves to cover unforeseen emergency or other unexpected need for funds.

Given the above, the Trustees have allocated funds to research projects aligned with the Research Strategy launched in April 2018.

#### Structure, governance and management

The Aplastic Anaemia Trust was incorporated on 8 July 2004 as a company limited by guarantee and not having a share capital and is governed by its Memorandum and Articles of Association. The company's registration number is 5174065. The company was registered with the Charity Commission for England and Wales as a charity with effect from 10 January 2005, under registration number 1107539. The company registered with the Office of the Scottish Charity Regulator (OSCR) with effect from 10 December 2019 under registration number SC049810.

#### **Recruitment & appointment of Trustees**

When recruiting new Trustees, the Trust looks for individuals with skills and experience which are considered of value to the charity and which are not necessarily held by existing Trustees. Potential Trustees are interviewed by existing Trustees and, if appointed, are provided with a pack of information including, inter alia, a copy of the most recent annual report and financial statements, a copy of the charitable company's Memorandum and Articles of Association and minutes of recent Trustee meetings. New Trustees then sign a declaration of willingness to act as a charity Trustee before being eligible to vote.

### Trustees

The Trustees, who are also Directors of the charitable company, who served during the year and to the date of this report were:

Professor E Gordon-Smith (resigned 4 July 2019)
A J Zucker (resigned 9 January 2019)
P M Cossell
S Moos
Professor J C W Marsh
Professor G Mufti
E Hanham
J L Cozens
M R Arnold (resigned 29 April 2020)
Professor P Hillmen
Dr S R Samarsinghe (appointed 30 October 2019)
A Conquy (appointed 29 April 2020)
T Stephenson (appointed 29 April 2020)

The Trustees are also Members of the charitable company. The charitable company is limited by guarantee and does not have a share capital. In the event that the charity is dissolved while a member remains a member, or within 12 months afterwards, every member has agreed to contribute up to £100 towards the costs of dissolution and the liabilities incurred by the charitable company while the contributor was a member.

THE APLASTIC ANAEMIA TRUST (Company number: 5174065)

(Charity number: 1107539)

### TRUSTEES' REPORT (INCORPORATING THE DIRECTORS' REPORT) (continued)

#### **Chief Executive**

The Trustees have delegated day-to-day management of the Trust's affairs to Grazina Berry during this financial period.

#### **Company Secretary**

The company secretary is Ms S L Tyler (appointed on 1 July 2020 to replace Ms G Berry who previously served as secretary).

#### Related party transactions

Notes 3, 5 and 6 to the accounts provide details of transactions with related parties.

#### **Advisers**

#### **Bankers**

CAF Bank Ltd 25 Kings Hill Avenue Kings Hill West Malling Kent ME19 4JQ

#### Independent Examiner

Leonard Jones & Co 1 Printing House Yard London E2 7PR

#### Registered Office/Principal Office

1 Printing House Yard London E2 7PR

#### Trustees' Responsibilities

Company law requires the Directors (who are also Trustees for the purposes of charity law) to prepare financial statements for each financial year. Under the law the Directors have elected to prepare the financial statements in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). Under company law the Directors must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and of its surplus or deficit for that period. In preparing the financial statements, the Directors are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles of the SORP (FRS102);
- make judgments and accounting estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The Directors are responsible for keeping adequate accounting records that are sufficient to show and explain the company's transactions and disclose with reasonable accuracy at any time the financial position of the company 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 company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

# TRUSTEES' REPORT (INCORPORATING THE DIRECTORS' REPORT) (continued)

#### Trustees' Responsibilities (continued)

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

# Small company rules / accounting policies

The accounts are prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

The financial statements have been prepared in accordance with the accounting policies set out in notes to the accounts and comply with the charity's governing document, 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 (effective January 2019) ("the SORP (FRS 102)"), FRS102, the Companies Act 2006, the Charities and Trustees Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006.

Approved by the Trustees and signed on their behalf on 3 9 2020 by:

1 2

#### INDEPENDENT EXAMINER'S REPORT TO TRUSTEES OF THE APLASTIC ANAEMIA TRUST

I report on the accounts of the charitable company for the year ended 31 March 2020, which are set out on pages 15 to 26.

#### Responsibilities and basis of report

As the company's trustees (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 ('the 2005 Act'), the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Companies Act 2006 ('the 2006 Act'). You are satisfied that the accounts of the company are not required by charity or company law to be audited and have chosen instead to have an independent examination.

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and eligible for independent examination, I report in respect of my examination of the company's accounts as carried out under section 44 (1) (c) of the 2005 Act and section 145 of the Charities Act 2011 (the '2011 Act'). In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

#### Independent examiner's statement

Since the company's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. Furthermore, since the company is required by company law to prepare its accounts on an accruals basis and is registered as a charity in Scotland your examiner must be a member of a body listed in Regulation 11 (2) of the Charities Accounts (Scotland) Regulations 2006 (as amended). I can confirm that I am qualified to undertake the examination because I am a registered member of the Institute of Chartered Accountants in England and Wales which is one of the listed bodies in both cases.

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:

- accounting records were not kept in respect of the charitable company as required by section 386 of the 2006 Act and Regulation 4 of the 2006 Accounts Regulations; or;
- the accounts do not accord with those records with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006; or;
- the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than
  any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of
  an independent examination; or
- the accounts have not been prepared in accordance with the methods and principles of the Statement of
  Recommended Practice for accounting and reporting by charities applicable to charities preparing their
  accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland
  (FRS 102).

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

D A Lyons, FCA
Partner in Leonard Jones & Co
Chartered Accountants
1 Printing House Yard
London E2 7PR

15 October 2020

# STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)

#### FOR THE YEAR ENDED 31 MARCH 2020

FOR THE YEAR ENDED 31 MARCH 2020					
		2020	2020	2020	2019
		Unrestricted	Restricted	Total	Total
		Funds	Funds	Funds	Funds
	Notes		(0) - 0 - 42)		(5) - 5 - 4.4)
		•	(Note 12)	•	(Note 14)
		£	£	£	£
Income from:		45454		45454	407.247
Donations & legacies		154,741		154,741	107,247
Grants receivable		13,338	83,320	96,658	219,864
Fund-raising events		26,298	-	26,298	40,493
Other trading activities		2,111	•	2,111	1,737
Total income		196,488	83,320	279,808	369,341
Expenditure on:					
Raising funds	4	42,770	*	42,770	24,912
Charitable activities:					
Patient Information, Outreach & Support	, 4	36,478	78,042	114,520	75,891
Research & Grants	4	183,677	•	183,677	154,670
		220,155	78,042	298,197	230,561
Total expenditure		262,925	78,042	340,967	255,473
Net (expenditure) / income for the year					
And net movement in funds		(66,437)	5,278	(61,159)	113,868
Total funds at 1 April 2019		347,834	219,864	567,698	453,830
Total funds at 31 March 2020		281,397	225,142	506,539	567,698
		<del></del>		<del></del>	

There were no other recognised gains or losses other than the net income above. There were no discontinued activities during the year or the previous year. The above statement, down to the item "Net (expenditure) /income for the year" constitutes an income and expenditure account.

The notes on pages 17 to 26 form part of these financial statements.

### BALANCE SHEET AS AT 31 March 2020

	Note	£	31.03.2020 £	£	31.03.2019 £
Current assets					
Debtors Cash at bank and in hand	9	120,284 637,027		221,681 470,890	
		757,311	_	692,571	
Creditors: amounts falling due within one year	10	(118,066)		(63,648)	
NET CURRENT ASSETS			639,245		628,923
TOTAL ASSETS LESS CURRENT LIABILITIES		-	639,245		628,923
Creditors: amounts falling due in more than one year	11		(132,706)		(61,225)
NET ASSETS	13	-	506,539		567,698
Reserves:					
Unrestricted funds Restricted funds	12		281,397 225,142		347,834 219,864
		_			
	13	_	506,539		567,698

The Trustee-Directors consider that the charitable company is entitled to exemption from the requirement to have an audit under the provisions of section 477 of the Companies Act 2006. Members have not required the charitable company to obtain an audit of its accounts for the year ended 31 March 2020 in accordance with section 476 of the Act.

The Trustee-Directors acknowledge their responsibilities for ensuring that the charitable company keeps accounting records which comply with section 386 of the Companies Act 2006, and for preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at 31 March 2020 and of its deficit the year then ended in accordance with the requirements of section 396, and which otherwise comply with the requirements of the Act relating to the financial statements so far as applicable to the charitable company.

The financial statements have been prepared in accordance with the special provisions relating to companies subject to the small companies regime within Part 15 of the Companies Act 2006 relating to small companies.

Approved by the Board of Trustees on 3 September 2020 and signed on its behalf by:

Sven Moos Trustee / Director

The notes on pages 17 to 26 form part of these financial statements.

(Company number: 5174065) (Charity number: 1107539)

# NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2020

#### 1. COMPANY INFORMATION

The Aplastic Anaemia Trust is a private company limited by guarantee registered in England and Wales, registration number is 5174065. The registered office is 1 Printing House Yard, London, E2 7PR.

The company is a registered charity, registered in England and Wales, registration number 1107539 and in Scotland under registration number SC049810.

#### 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

#### (a) Basis of preparation

The financial statements have been prepared under the historical cost convention, on a going concern basis, in accordance with the Charity Commissioners' "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" (effective January 2019) ("the SORP (FRS 102)"), FRS 102, the Charities and Trustees Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006, the Charities Act 2011 and the Companies Act 2006.

The charitable company constitutes a public benefit entity as defined by FRS 102.

The financial statements are denominated in pounds sterling ("£").

#### (b) Going Concern

The Trustees consider there are no material uncertainties about the charitable company's ability to continue as a going concern. The review of the financial position and future plans gives Trustees confidence that the charity remains a going concern for the foreseeable future.

#### (c) Statement of Financial Activities ("SoFA") / Income and Expenditure Account

The format differs from that for a profit & loss account prescribed by the Companies Act 2006, the Trustee – Directors being of the opinion that the format adopted reflects more fairly the activities of the charity.

#### (d) Taxation

The company is a registered charity and is not subject to UK corporation tax.

# (e) Cash flow statement

The financial statements do not include a cash flow statement because the charitable company meets the criteria for exemption from the requirement to prepare such a statement under the SORP (FRS 102).

#### (f) Fund Accounting

Unrestricted general funds are the accumulated surpluses on general charitable funds which can be used in the furtherance of the objectives of the charity at the discretion of the Trustees.

Restricted income funds are charitable funds to be utilised for a particular charitable purpose as specified by donors.

# NOTES TO THE ACCOUNTS (continued) FOR THE YEAR ENDED 31 MARCH 2020

#### 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (continued)

#### (g) Income

All income is recognised and included in the SoFA when the charity has entitlement to the income, it is probable that the income will be received and the amount can be measured reliably.

Legacies are recognised following grant of probate when the charity has been notified of both the amount and the expected settlement date or on date of receipt of funds, if earlier. In the event of a gift of an asset other than cash or investments traded on a recognised stock market, recognition is subject to the asset being reliably measurable and title having been transferred. Income is not recognised from legacies which remain subject to a life interest.

#### (h) Expenditure

Expenditure is accounted for on an accruals basis and classified under headings in the accounts that aggregate all costs related to the category.

Expenditure in respect of raising funds includes the costs incurred in generating voluntary income and fundraising activity. These costs are regarded as necessary to generate funds to finance charitable activities.

Charitable activities expenditure includes the costs identified as wholly or mainly attributable to the achieving the charitable objectives. These include direct staff and activity costs, wholly or mainly attributable support cost and an apportionment of general overheads.

Grants payable are accounted for when the recipient has been notified of the award except where future payments are conditional on performance and specific deliverables. In such cases, grants payable are accounted for as expended when such conditions have been met.

Support costs are general costs which enable the charity's activities to be undertaken. These include office functions such as accounting and information systems. Support costs also include the costs of governance, which relate to the general running of the charity as opposed to direct operational management. They include costs of the governance infrastructure including constitutional and statutory costs, independent examiner's fees, legal advice for Trustees and costs associated with the strategic management of the charity's activities.

The charitable company is not registered for VAT and so all expenditure is shown inclusive of VAT.

# (i) Pensions

The charitable company operates a defined contribution pension scheme, through contributions to NEST or employee personal pension scheme. Contributions are charged to the profit and loss account as they become payable.

#### (j) Debtors

Debtors are recognised at the settlement amount due. Prepayments are valued at the amount prepaid.

### (k) Creditors and provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount.

# NOTES TO THE ACCOUNTS (continued) FOR THE YEAR ENDED 31 MARCH 2020

# 2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (continued)

#### (I) Cash at bank and in hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

#### (m) Financial instruments

The charitable company only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

#### (n) Material judgments and uncertainties

The preparation of the financial statements requires management to make judgments, estimates and assumptions that affect the amounts reported for assets and liabilities as at the balance sheet date and the amounts reported for income and expenditure during the year. The nature of estimation means the actual outcomes could differ from those estimates. There are no judgments made that have a significant effect on the amounts recognised in the financial statements.

#### 3. TRUSTEE REMUNERATION AND TRANSACTIONS

The Trustees received no remuneration during the year or the preceding year nor were any Trustee expenses incurred in either the current or preceding year.

# 4. EXPENDITURE

Direct activity costs	Grants (note 5)	Support costs (note 7)	31.03.2020 Total	31.03.2019 Total
£	£	<b>.</b>	£	£
42,770	-	-	42,770	24,912
99,927	-	14,593	114,520	75,891
16,433	152,652	14,592	183,677	154,670
159,130	152,652	29,185	340,967	255,473
	activity costs £ 42,770 99,927 16,433	activity Grants costs (note 5) £ £ 42,770 - 99,927 - 16,433 152,652	activity Grants costs costs (note 5) (note 7) £ £ £  42,770 -  99,927 - 14,593 16,433 152,652 14,592	activity Grants costs 31.03.2020 costs (note 5) (note 7) Total £ £ £  42,770 - 42,770  99,927 - 14,593 114,520 16,433 152,652 14,592 183,677

# Year ended 31 March 2019:

	Direct activity costs £	Grants (note 5) £	Support costs (note 7) £	31.03.2019 Total £
Raising Funds:				
· Cost of raising funds	24,912	-	-	24,912
Charitable Activities:				
Patient information, outreach & support	63,229	-	12,662	75,891
Research & grants	21,283	120,725	12,662	154,670
	109,424	120,725	25,324	255,473

# NOTES TO THE ACCOUNTS (continued) FOR THE YEAR ENDED 31 MARCH 2020

#### 5. RESEARCH & GRANTS

Research grants (to institutions):	31.03.2020 £	31.03.2019 £
Kings College London (see a. below)	152,652	-
Kings College London (see b. below)	-	66,439
Great Ormond Street Hospital (see c. below)	-	54,286
	152,652	120,725

- a. Kings College London grant: AAT has committed £152,652 towards a 3 year research project entitled "Production of expanded autologous regulatory T cells to treat patients with refractory aplastic anaemia in a phase I dose study." This research is being led by Prof. Mufti, who is a Trustee of AAT.
- b. Kings College London grant: This was a 2 year commitment, payable quarterly in order to fund research into the identification and relevance of novel somatic mutations in aplastic anaemia. This research is being overseen by Prof. Marsh, who is a Trustee of AAT.

Of the £66,439 committed during the year ended 31 March 2019, £8,305 was payable in the year ended 31 March 2019, £33,220 during the year ended 31 March 2020 and £24,914 is payable during the year ending 31 March 2021. At 31 March 2020 £24,915 of the total amount payable had not yet been paid over (2019: £8,305 had not been paid over).

c. Great Ormond Street Hospital grant: This was a 3 year commitment aiming to establish a UK bone marrow failure registry and biobank.

Of the £54,286 committed during the year ended 31 March 2019, £17,975 was payable (and was paid) during the year ended 31 March 2020, £18,095 is payable during the year ending 31 March 2021 and £18,216 during the year ending 31 March 2022. This research is being conducted by Dr Samarsinghe, who became a Trustee of AAT during the year.

(Company number: 5174065) (Charity number: 1107539)

# NOTES TO THE ACCOUNTS (continued) FOR THE YEAR ENDED 31 MARCH 2020

#### 6. EMPLOYEES

	31.03.2020 £	31.03.2019 £
Wages & salaries	103,857	98,100
National insurance costs	8,108	8,294
Other pension costs	3,970	3,862
Other benefits	225	-
	116,160	110,256
	No	No
The average number of was:	3	2

During the year ended 31 March 2019 £4,414 was payable in respect of redundancy and termination payments, all of which was settled at that year end. There were no equivalent payments during the year ended 31 March 2020.

The number of employees receiving employee benefits (excluding employer		
pension costs & NI) of more than £60,000 were:	No	No
£70,000-£79,000	1	1

# **Key Management Personnel**

Key Management Personnel are defined as those to whom Trustees have delegated day-to-day management of activities and who report to the Trustees. The total employee remuneration and benefits (including employer pension and national insurance contributions) received by the key management personnel was £85,511 (2019: £85,413).

(Charity number: 1107539)
NOTES TO THE ACCOUNTS (continued)
FOR THE YEAR ENDED 31 MARCH 2020

#### 7. SUPPORT COSTS

These form part of overall expenditure (see note 4):

	Governance (Note 8)	Staff related costs*	Storage, office costs & equipment	Bank & similar charges	31.03.2020 Total	31.03.2019 Total
	£	£	£	£	£	£
Raising funds:						
Cost of raising funds	-	-	-	-	-	-
Charitable activities: Patient information &						
support	7,613	2,577	4,373	30	14,593	12,662
Research & grants	7,612	2,578	4,372	30	14,592	12,662
	15,225	5,155	8,745	60	29,185	25,324

<sup>\*</sup>Including recruitment and staff travel costs not directly attributable.

Support costs have been allocated to activities on the following bases:

- Staff costs are allocated on the basis of estimated time spent.
- Other support costs are allocated on estimated usage.

Year ended 31 March 2019:

	Governance (Note 8)	Staff related costs*	Storage, office costs & equipment	Bank & similar charges	31.03.2019 Total
	£	£	£	£	£
Raising funds:					
Cost of raising funds	-	-	•	-	-
Charitable activities: Patient information &					
support	7,565	866	2,966	1,265	12,662
Research & grants	7,565	866	2,966	1,265	12,662
	15,130	1,732	5,932	2,530	25,324

# 8. GOVERNANCE COSTS

	. 31.03.2020 £	31.03.2019 £
Professional fees Staff costs	2,900 12,325	2,360 12,770
•	15,225	15,130

Professional fees represent amounts payable to the independent examiner and include accountancy fees of £1,450 (2019: £1,000) and independent examination fees of £1,450 (2019: £1,360).

# NOTES TO THE ACCOUNTS (continued) FOR THE YEAR ENDED 31 MARCH 2020

#### 9. DEBTORS

	31.03.2020 £	31.03.2019 £
Grants and donations receivable (see below) Other debtors	108,972 11,312	219,864 1,817
	120,284	221,681

AAT were notified in March 2019 that they were to be awarded a grant of £219,864 by The National Lottery Community Fund in relation to the design and implementation of a 2 year project known as "MarrowKidz". The grant is receivable in payments at six monthly intervals. Two amounts were received during the year totalling £133,392 (2019: £ nil received), leaving £86,472 as receivable at the year end. Of the total amount receivable none is receivable in more than 12 months from the balance sheet date (2019: £86,472 due in more than one year).

By 31 March 2020 AAT had been notified of grants and donations totalling £22,500 as receivable in relation to its Covid-19 emergency response appeal. These amounts were received shortly after the year end.

# 10. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

		31.03.2020 £	31.03.2019 £
	Research grant commitments Accruals	106,086 11,980	51,195 12,453
		118,066	63,648
11.	CREDITORS: AMOUNTS FALLING DUE IN MORE THAN ONE YEAR		
		31.03.2020 £	31.03.2019 £
	Research grant commitments	132,706	61,225

# NOTES TO THE ACCOUNTS (continued) FOR THE YEAR ENDED 31 MARCH 2020

#### 12. RESTRICTED FUNDS

Restricted funds and movements during the year were as follows:

	At 1 April 2019 £	Income £	Expenditure £	At 31 March 2020 £	At 31 March 2019 £
Marrowkidz Fund Patient Information, Outreach & Support Programme Fund	219,864	- 51,170	(61,243) (16,785)	158,621 34,385	219,864
Emergency response – COVID-19 Fund	-	32,150	(14)	32,136	-
	219,864	83,320	(78,042)	225,142	219,864

Year ended 31 March 2019:

	At 1 April 2018	Income	Expenditure	At 31 March 2019
	£	£	£	£
Marrowkidz Fund		219,864	-	219,864

Marrowkidz Fund: This fund relates to a National Lottery Community Fund grant to plug the gap in the availability of age-appropriate information and support resources aimed at children, young people and their families living with AA; key deliverables including an interactive resource library; regional peer-to-peer young people support networks; consistency and excellence in diagnosis and treatment guidelines; and awareness raising and promotion activities.

Patient Outreach, Support & Information Programme Fund: This fund relates to a national aplastic anaemia Support and Outreach Programme, which combines Family Information Events — bringing together patient communities and key haematology experts across the UK's regions, connected clinicians involved in the treatment of patients with AA and allied rare bone marrow failures with families affected by AA. Providing them with an overview of treatments available, any new developments and information on support available; and informal local peer-to-peer meetings enabling mutual support and leading to positive psycho-social impact.

Emergency Response – COVID-19 Fund: This fund supports changes to our means of supporting shielded and vulnerable patients, by transforming peer-to-peer support sessions into digital support meetings throughout England, Scotland, Wales and Ireland; to influence rapid production of specific guidance on how to deal with the pandemic aimed at paediatric and adult AA populations which were distributed through our website and social media channels; and offer to our patient communities two interactive webinars with leading clinicians to help them understand better what shielding meant and the impact of the pandemic on their treatment and recovery.

# NOTES TO THE ACCOUNTS (continued) FOR THE YEAR ENDED 31 MARCH 2020

# 13. ANALYSIS OF NET ASSETS BETWEEN FUNDS

<b>.</b>	Unrestricted Funds	Restricted Funds	Total
,	£	£	£
Current assets	532,169	225,142	757,311
Creditors due with 1 year	(118,066)	-	(118,066)
Creditors due in more than 1 y	year (132,706)	-	(132,706)
	281,397	225,142	506,539
Year ended 31 March 2019:			
	Unrestricted	Restricted	<b>T</b> -A-1
	Funds £	Funds £	Total £
Current assets	472,707	219,864	692,571
Creditors due with 1 year	(63,648)	-	(63,648)
Creditors due in more than 1 y		-	(61,225)
	347,834	219,864	567,698

# NOTES TO THE ACCOUNTS (continued) FOR THE YEAR ENDED 31 MARCH 2020

# 14. COMPARATIVE STATEMENT OF FINANCIAL ACTIVITIES

	Notes	2019 Unrestricted Funds	2019 Restricted Funds (Note 14)	2019 Total Funds
		£	£	£
Income from:				
Donations & legacies		107,247	-	107,247
Grants receivable	9	-	219,864	219,864
Fund-raising events		40,493	-	40,493
Other trading activities		1,737	-	1,737
Total income		149,477	219,864	369,341
Expenditure on:				
Raising funds	4	24,912	-	24,912
Charitable activities:				
Patient Information & Support	4	75,891	-	75,891
Research & Grants	4	154,670	=	154,670
		230,561	-	230,561
Total expenditure		255,473	-	255,473
Net (expenditure) / income for the year and net movement in funds		(105,996)	219,864	. 113,868
Reconciliation of funds: Total funds at 1 April 2018		453,830		453,830
Total funds at 31 March 2019		347,834	219,864	567,698

There were no other recognised gains or losses other than the net income above. There were no discontinued activities during the year or the previous year. The above statement, down to the item "Net income for the year" constitutes an income and expenditure account.