

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2020
FOR
DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK

Ashdown Hurrey Auditors Limited
Statutory Auditors
20 Havelock Road
Hastings
East Sussex
TN34 1BP

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FOR THE YEAR ENDED 31 DECEMBER 2020

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MESSAGE FROM THE CHAIR, LEISA BATKIN
FOR THE YEAR ENDED 31 DECEMBER 2020

2020 was an unprecedented year for us all and we faced true adversity both personally and as a Charity.

The pandemic was an extremely difficult time for the families affected with DBA. When the first lockdown was nationally instructed all our children and adults with DBA were instructed to shield, removing them from school, jobs, friends and loved ones. We recognised that national information was at times confusing and unhelpful and our families were very anxious. As a charity we organised virtual monthly updates with our clinical teams with our families to talk with the medical team to support decision making. We supported the medical team to develop clear guidelines, we also organised a meeting with a member of SAGE to talk through our issues and directly report back to the Government. We anticipated we were unable to host our brilliant weekend away, so we organised a virtual conference which included international delegates and over 100 people attended over the two days. We continued throughout the year with frequent updates via social media platforms, literature and webinars. Our families felt supported and connected and it was really important that we offered this guidance that was up to date, relevant and easy to understand. We provided our families with masks, letters for schools, signposted to employment support services and offered a place to discuss issues and difficult decisions.

We were very fortunate to be offered a grant to be able to send our families a voucher to help with their Christmas shopping and gifts. We couldn't be together, but we could look after each other. Unsurprisingly, throughout this we have come out stronger, closer and more activated to make changes. We have worked with the clinical team to promote e-reviews and virtual appointments with our specialist in London. We have also provided funding to ensure the research underway is future proofed and real changes to our treatment plan will be made.

During the lockdowns we also developed a good working relationship with a digital team who have developed patient information leaflets with our guidance. These are now available as hard or digital copies for all our families and health care workforce. Throughout all of this our committee stands at just 4 people. This reduced number remains a strong cohort who turn to each other for support, recognise the value in each other and provide such a huge amount of support to our families. It is a privilege to be a part of this small, but amazing team. We are hoping 2021 is kinder to us all, but in the meantime, we will endeavour to support our families as much as we can.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2020

The trustees present their report with the financial statements of the charity for the year ended 31 December 2020. The trustees have adopted the provisions of 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) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

a) For the relief of sickness of those suffering either directly or indirectly from Diamond Blackfan Anaemia (DBA) and associated conditions.

b) To educate the general public through promotion of research and the dissemination of knowledge about Diamond Blackfan Anaemia (DBA).

Significant activities

Sadly, due to the restrictions of the Covid pandemic, our Annual Family Weekend at Caythorpe Court PGL centre in Lincolnshire was cancelled this year. So, we could not meet with our families in person.

However, we organised a 'two-day' virtual conference via Zoom which included international delegates and speakers. The event was hugely successful with over 100 people attending over the two days. The response was so good that we have introduced regular, topic-specific webinars as part of our ongoing support service.

Annual Adult Patient Conference

Every year we organise and host an annual residential weekend in London just for our adults with DBA. We invite lead clinicians to talk to our adult patients to manage their condition may be more relevant to adults rather than children. Fortunately, we managed to hold this event in February, prior to the Covid outbreak in March. This year brought together many of our adult DBA patients living in the UK. Once again, the weekend was a huge success with positive feedback from all our attendees.

Support of DBA Research and improved clinical management techniques.

Although we are a relatively small charity, we support research projects from all around the world, all trying to discover and understand the mechanisms for the occurrence of DBA and to improve the management of the condition.

Dr Deena Iskander of Imperial College London has been working on her own DBA research projects for the last few years and we have funded this work in the past. This year Deena asked if we could again provide funding for a research assistant to support her current project which we were delighted to be able to do. (£30K)

We also continued to support the exciting research of Dr Devon Germain, currently based at the University of Vienna in Austria. This is Year 2 of a 3-year project supported by DBA UK (£10K per year)

Once again, we made a contribution of \$20,000 USD (£16,047) to the DBAF International Consensus Conference in Atlanta, USA. This event brings together DBA specialists, consultants and researchers from all over the world to share knowledge and establish common standards of treatment and management for DBA. Unfortunately, the event was postponed due to Covid travel restrictions but will hopefully take place in 2021.

Online support through Social Media via our website

Support via social media became even more important during the Covid pandemic in 2020. DBA UK Facebook pages continue to be an invaluable source of support for all our DBA patients and families. We also have a website which is packed with information relating to DBA. Next year we are planning to rebuild the website, reviewing its content and making more user friendly for mobile phones and tablets. We are also investigating the potential to develop an online app for our families to use. The goal for this is for our families to record test results, plan hospital appointments, have easy access to important information and to manage their child's treatment and care from one central location.

Telephone Helpline

DBA UK continue to provide a telephone helpline for DBA support. However, with the increasing popularity of social media, we receive very few telephone calls. Our focus has therefore switched to online support via our Facebook pages which have proved hugely successful.

Information Leaflets

DBA UK have produced new and much improved information leaflets which we regularly circulate and provide as downloads via our website. This reflects the changing approaches to DBA treatment and management.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2020

ACHIEVEMENT AND PERFORMANCE

Sadly, due to the restrictions of the Covid pandemic, our Annual Family Weekend at Caythorpe Court PGL centre in Lincolnshire was cancelled this year. So, we could not meet with our families in person.

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We also continued throughout the year with frequent updates via social media platforms, literature and webinars. Our families felt supported and connected. It was really important that we offered guidance that was up to date, relevant and easy to understand. We provided our families with masks, letters for schools, signposted to employment support services and offered a place to discuss issues and difficult decisions.

In this exceptional year, our committee and trustees have worked tirelessly to support our DBA families and patients. Some of whom have been through or are going through the Bone Marrow Transplant process with their children. This is a hugely stressful and emotional journey and we are very fortunate to have families who can help us share their support and BMT experiences.

FINANCIAL REVIEW

Financial Review

Despite there being very few fundraising events for most of the year, 2020 saw an excellent annual income of £78,976. This was boosted by a donation of £20K from one of our very close DBA families, the Rose family with their hugely successful 'Rose Ball'. We were also very grateful to receive a grant for £14,200 from 'Contact A Family'. Another of our amazing DBA families, the Rhodes family successfully applied for the grant on our behalf.

Our total expenditure 2020 was £76,735

Notable expenditure included;

- Contribution to DBAF ICC 2020 in Atlanta	£16,047
- Dr Devon Germain Research Year 2 of 3 (Austria)	£10,000
- Dr Deena Iskander (support for Research Assistant)	£30,000

Total cash assets at 31 December 2020	£88,334
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Reserves policy

Our annual Family Weekend remains the core event for our charity. Consequently, the Committee have decided that the charity should hold "3 years costs for Family Weekends" in reserve. Currently each Family Weekend costs the charity approximately £25,000 so we must therefore hold £75,000 in reserve.

FUTURE FUNDRAISING OBJECTIVES AND PLANS

The Committee acknowledge that going forward the charity will have to work harder to secure a good annual income. This may involve exploring other sources of income such as corporate sponsorships and grants. The committee discussed the possibility of seeking external advice on putting together a fundraising strategy for the charity. However, we are aware that putting such a strategy into practice may be challenging given that we rely heavily on such a small group of volunteers. We acknowledge that a great contribution is made by our committee volunteers and we are grateful for the many hours they have spent sharing their skills, knowledge and experience. Without this valuable contribution, we would not have been able to achieve so much this year. However, like most charities, we must actively make provision to recruit new Committee members to support the few we have currently.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust and constitutes an unincorporated charity.

Recruitment and appointment of new trustees

Election from members at AGM on 3 Year rotation, 1/3rd resigning in turn each year, who are then eligible for re-election at our AGM usually held at our Family Weekend usually in May.

Trustees give their time voluntarily and generally receive no remuneration or other benefits. However, as a temporary emergency measure, Leisa Batkin, our Chair and Trustee receives a small sum per month to secure time for the vital work she does for the charity. This will be reviewed as and when new Committee members are recruited and the workload is reduced for the few committee members we currently have.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2020

STRUCTURE, GOVERNANCE AND MANAGEMENT

Committee Roles and Responsibilities

Unfortunately, this year saw two more committee members step down as Trustees. This effectively leaves us with four active committee members and one honorary member. Like many other charities, we struggle to find volunteers who are willing to commit their time and skills to our cause. Naturally, this puts even more pressure on our existing volunteers who already work tirelessly to support the charity. We recognise that this situation is not sustainable so next year it is our primary goal to recruit new volunteers onto the Committee.

We continued to fund Leisa Batkin, our most medically qualified and experienced committee member (and Chair), on a 'consultancy basis' for a set number of hours per week. This ensures that Leisa can dedicate her precious time to supporting our volunteer committee until such a time that we could recruit more new members. This temporary arrangement has proved to be a huge success and we are extremely very grateful to Leisa for her continued commitment.

Risk management

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number
1083179

Principal address

71-73 Main Street
Palterton
Chesterfield
Derbyshire
S44 6UR

Trustees

J Whitaker
L Batkin
P Redmond
M D Winter (resigned 17.5.20)
H S Till
J Hubbard
L Watson (resigned 1.2.20)

Independent Examiner

Ashdown Hurrey Auditors Limited
Statutory Auditors
20 Havelock Road
Hastings
East Sussex
TN34 1BP

PUBLIC BENEFIT

In line with the Charity Commission's guidance on public benefit, the charity regularly reviews its objects and achievements in order to ensure that the guidelines are complied with. Following the cessation of the courses at Preston College the trustees are in consultation with the Charity Commission in order to ensure that funds continue to be used in accordance with the charity's objectives and the Commission's guidelines.

Approved by order of the board of trustees on 29 October 2021 and signed on its behalf by:

P Redmond - Trustee

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK

Independent examiner's report to the trustees of Diamond Blackfan Anaemia Support Group UK
I report to the charity trustees on my examination of the accounts of Diamond Blackfan Anaemia Support Group UK (the Trust) for the year ended 31 December 2020.

Responsibilities and basis of report

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

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

Independent examiner's statement

I have completed my examination. I confirm that no material 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 Trust as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

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

S R Sampson FCA FCIE DChA
Ashdown Hurrey Auditors Limited
Statutory Auditors
20 Havelock Road
Hastings
East Sussex
TN34 1BP

29 October 2021

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 DECEMBER 2020

		31.12.20 Unrestricted fund £	31.12.19 Total funds £
INCOME AND ENDOWMENTS FROM	Notes		
Donations and legacies		70,360	65,911
Other trading activities	3	8,532	5,850
Investment income	4	84	231
Total		<u>78,976</u>	<u>71,992</u>
EXPENDITURE ON			
Raising funds		1,006	5,452
Other		<u>75,729</u>	<u>114,066</u>
Total		<u>76,735</u>	<u>119,518</u>
NET INCOME/(EXPENDITURE)		2,241	(47,526)
RECONCILIATION OF FUNDS			
Total funds brought forward		85,253	132,779
TOTAL FUNDS CARRIED FORWARD		<u><u>87,494</u></u>	<u><u>85,253</u></u>

The notes form part of these financial statements

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK

BALANCE SHEET
31 DECEMBER 2020

		31.12.20 Unrestricted fund £	31.12.19 Total funds £
CURRENT ASSETS	Notes		
Cash at bank		88,334	86,003
CREDITORS			
Amounts falling due within one year	8	(840)	(750)
NET CURRENT ASSETS		<u>87,494</u>	<u>85,253</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		87,494	85,253
NET ASSETS		<u>87,494</u>	<u>85,253</u>
FUNDS	9		
Unrestricted funds		<u>87,494</u>	<u>85,253</u>
TOTAL FUNDS		<u>87,494</u>	<u>85,253</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 29 October 2021 and were signed on its behalf by:

P Redmond - Trustee

L Batkin - Trustee

H S Till - Trustee

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2020

1. STATUTORY INFORMATION

Diamond Blackfan Anaemia Support Group is an unincorporated charity, registered in England & Wales. The charity's registered number and principal address can be found in the Report of the Trustees.

2. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) '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) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

In preparing the financial statements, the trustees are required to make an assessment of the ability of the charity to continue as a going concern. The trustees have considered all available evidence for the charity which covers the 12 month period from the date of signing these financial statements. Against the backdrop of the COVID-19 Pandemic the trustees have paid particular attention to likely cashflow requirements and the future availability of adequate cashflow to the charity.

On the basis of this consideration, the trustees are satisfied that the charity has adequate resources to continue in operational existence and to meet its liabilities as they fall due for the foreseeable future. In reaching this conclusion they consider that no material uncertainty exists. As a result, the trustees have concluded that it remains appropriate to adopt a going concern basis of preparation in these financial statements.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Taxation

The charity is exempt from tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 DECEMBER 2020

3. OTHER TRADING ACTIVITIES

	31.12.20	31.12.19
	£	£
Fundraising events	<u>8,532</u>	<u>5,850</u>

4. INVESTMENT INCOME

	31.12.20	31.12.19
	£	£
Deposit account interest	<u>84</u>	<u>231</u>

5. INDEPENDENT EXAMINERS' REMUNERATION

	31.12.20	31.12.19
	£	£
Fees payable to the charity's independent examiners for the independent examination of the charity's financial statements	<u>840</u>	<u>750</u>

6. TRUSTEES' REMUNERATION AND BENEFITS

During the year Trustee; L Batkin was remunerated for consultancy services totalling £4,800 (2019: £2,900). This is permitted in accordance with a resolution dated 9 July 2019 updating the Trustee Benefit Clause in the Charity's Governing Document which was approved by the Charity Commission.

Trustees' expenses

Expenses totalling £489 were paid to one Trustee during the year in relation to travel expenses.

7. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £
INCOME AND ENDOWMENTS FROM	
Donations and legacies	65,911
Other trading activities	5,850
Investment income	231
Total	<u>71,992</u>
EXPENDITURE ON	
Raising funds	5,452
Other	114,066
Total	<u>119,518</u>
NET INCOME/(EXPENDITURE)	<u>(47,526)</u>
RECONCILIATION OF FUNDS	
Total funds brought forward	132,779
TOTAL FUNDS CARRIED FORWARD	<u>85,253</u>

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 DECEMBER 2020

8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.12.20 £	31.12.19 £
Other creditors	<u>840</u>	<u>750</u>

9. MOVEMENT IN FUNDS

	At 1.1.20 £	Net movement in funds £	At 31.12.20 £
Unrestricted funds			
General fund	85,253	2,241	87,494
	<u>85,253</u>	<u>2,241</u>	<u>87,494</u>
TOTAL FUNDS	<u>85,253</u>	<u>2,241</u>	<u>87,494</u>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	78,976	(76,735)	2,241
	<u>78,976</u>	<u>(76,735)</u>	<u>2,241</u>
TOTAL FUNDS	<u>78,976</u>	<u>(76,735)</u>	<u>2,241</u>

Comparatives for movement in funds

	At 1.1.19 £	Net movement in funds £	At 31.12.19 £
Unrestricted funds			
General fund	132,779	(47,526)	85,253
	<u>132,779</u>	<u>(47,526)</u>	<u>85,253</u>
TOTAL FUNDS	<u>132,779</u>	<u>(47,526)</u>	<u>85,253</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	71,992	(119,518)	(47,526)
	<u>71,992</u>	<u>(119,518)</u>	<u>(47,526)</u>
TOTAL FUNDS	<u>71,992</u>	<u>(119,518)</u>	<u>(47,526)</u>

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 DECEMBER 2020

9. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined position is as follows:

	At 1.1.19 £	Net movement in funds £	At 31.12.20 £
Unrestricted funds			
General fund	132,779	(45,285)	87,494
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>132,779</u>	<u>(45,285)</u>	<u>87,494</u>

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	150,968	(196,253)	(45,285)
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>150,968</u>	<u>(196,253)</u>	<u>(45,285)</u>

10. RELATED PARTY DISCLOSURES

Transactions with Trustees during the year are summarised in note 6.