

REPORT OF THE TRUSTEES AND  
UNAUDITED FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31 DECEMBER 2021  
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 2021

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MESSAGE FROM THE CHAIR, LEISA BATKIN  
FOR THE YEAR ENDED 31 DECEMBER 2021

This is the 10th Chair's Report that I have had the privilege to present. In these unusual times it has been a privilege to support our families and help support them in accessing the right information at the right time during the pandemic of COVID-19.

2021 has been a challenging year with the COVID pandemic taking priority and cancelling our family weekend for the second year. However, we organised several virtual conferences which were very important for our families and help them remain connected. There is always some exciting opportunity just around every corner and it remains as important to DBA UK now to strive for the magic brought by its members as it did 20 years ago at the start of the Charity. We believe that we, as a charity have moved rapidly to respond to our family's needs.

Our little charity continues to deliver to all the members. This is all good news but requires a lot of work behind the scenes. The committee work tirelessly to raise funds, to support our families and support your amazing fundraising efforts. To allow any of this to happen is time consuming and more and more pressure is placed on these volunteers to perform. It is an increasingly difficult climate for fundraising. We are constantly challenged to maintain the income required to carry on. However, we will continue to work with corporate institutions and companies to support our finances.

I am pleased to report that we are thriving and it's thanks to the wonderful families supporting our fundraising goal that we feel secure in our future. We have further developed a 'Care Pathway' working with our clinical team in London, a funding pack to engage our families and funded work in Imperial London. We have also been able to develop some patient information leaflets which will support treatment, increase confidence for patients and help with decision making in local hospitals.

Perhaps one of the most significant and enriching changes in the last couple of years is our alliance with researchers and clinical leads, and the in collaboration of other UK charities active in red cell aplasia and bone marrow failures, this union brought with it new activities and ideas, initiated locally and providing a strong sense collaboration and belonging of the charity. We are working with new medics and have a wonderful ambassador to champion our Charity. We have developed a genetic passport that will track all blood tests so we are in control of what we give and understand why we do it.

We continue to work with Global Bridges and the DBAF and will continue to work effectively with them. DBA UK offers a unique combination of social interaction, family support, clinical management and scientific breakthrough in a combination that is transparent and accessible. DBA UK supports people to achieve best health outcomes regardless of location.

We will continue to support our families as much as we can using our designated support phone line, social media and email. We will also dedicate our efforts to ensure all national guidance is understood and bespoke webinars are scheduled with our clinical lead and nurse specialist, so family's and patients can discuss concerns and issues.

To end, DBA UK continues to outperform for a small charity and we are extremely proud of all we have achieved in these unprecedented times.

REPORT OF THE TRUSTEES  
FOR THE YEAR ENDED 31 DECEMBER 2021

The trustees present their report with the financial statements of the charity for the year ended 31 December 2021. 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 again 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. Unfortunately, the event had to be postponed this year due to the Covid pandemic.

##### 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 (£5K).

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

The Annual 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 again postponed due to Covid travel restrictions but will hopefully take place in 2022. DBA UK continue to financially support this event.

##### Online support through Social Media via our website

Support via social media became even more important during the Covid pandemic in 2021. 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 2021

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. 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.

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, 2021 saw an excellent annual income of £71,326.

Our total expenditure for 2021 was £30,598.

This was predictably low due to the ongoing Covid pandemic during 2021. The annual Family Weekend was again postponed and many research projects and requests for funding were temporarily suspended.

Notable expenditure this year included;

- Dr Devon Germain Research Year 3 of 3 (Austria)	£10,000
- Dr Deena Iskander (support for Research Assistant)	£5,000

Total cash assets at 31 December 2021	£129,062
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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 2021

STRUCTURE, GOVERNANCE AND MANAGEMENT

Committee Roles and Responsibilities

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 are truly grateful to the core four committee members who work tirelessly for the charity.

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  
H S Till  
J Hubbard

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 27 October 2022 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 2021.

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

Date: 28 October 2022

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP  
UK

STATEMENT OF FINANCIAL ACTIVITIES  
FOR THE YEAR ENDED 31 DECEMBER 2021

		31.12.21 Unrestricted fund £	31.12.20 Total funds £
INCOME AND ENDOWMENTS FROM	Notes		
Donations and legacies		68,831	70,360
Other trading activities	3	2,483	8,532
Investment income	4	12	84
Total		<u>71,326</u>	<u>78,976</u>
EXPENDITURE ON			
Raising funds		305	1,006
Other		30,293	75,729
Total		<u>30,598</u>	<u>76,735</u>
NET INCOME		40,728	2,241
RECONCILIATION OF FUNDS			
Total funds brought forward		87,494	85,253
TOTAL FUNDS CARRIED FORWARD		<u><u>128,222</u></u>	<u><u>87,494</u></u>

The notes form part of these financial statements



DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP  
UK

BALANCE SHEET  
31 DECEMBER 2021

	Notes	31.12.21 Unrestricted fund £	31.12.20 Total funds £
CURRENT ASSETS			
Cash at bank		129,062	88,334
CREDITORS			
Amounts falling due within one year	8	(840)	(840)
NET CURRENT ASSETS		<u>128,222</u>	<u>87,494</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		128,222	87,494
NET ASSETS		<u>128,222</u>	<u>87,494</u>
FUNDS	9		
Unrestricted funds		<u>128,222</u>	<u>87,494</u>
TOTAL FUNDS		<u>128,222</u>	<u>87,494</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 27 October 2022 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 2021

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 2021

3. OTHER TRADING ACTIVITIES

	31.12.21	31.12.20
	£	£
Fundraising events	<u>2,483</u>	<u>8,532</u>

4. INVESTMENT INCOME

	31.12.21	31.12.20
	£	£
Deposit account interest	<u>12</u>	<u>84</u>

5. INDEPENDENT EXAMINERS' REMUNERATION

	31.12.21	31.12.20
	£	£
Fees payable to the charity's independent examiners for the independent examination of the charity's financial statements	<u>840</u>	<u>840</u>

6. TRUSTEES' REMUNERATION AND BENEFITS

During the year Trustee; L Batkin was remunerated for consultancy services totalling £5,000 (2020: £4,800). 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 £190 were paid to one Trustee during the year in relation to travel expenses.

7. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £
<b>INCOME AND ENDOWMENTS FROM</b>	
Donations and legacies	70,360
Other trading activities	8,532
Investment income	84
<b>Total</b>	<u>78,976</u>
<b>EXPENDITURE ON</b>	
Raising funds	1,006
Other	75,729
<b>Total</b>	<u>76,735</u>
<b>NET INCOME</b>	2,241
<b>RECONCILIATION OF FUNDS</b>	
Total funds brought forward	85,253
<b>TOTAL FUNDS CARRIED FORWARD</b>	<u>87,494</u>

NOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 31 DECEMBER 2021

8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.12.21 £	31.12.20 £
Other creditors	<u>840</u>	<u>840</u>

9. MOVEMENT IN FUNDS

	At 1.1.21 £	Net movement in funds £	At 31.12.21 £
Unrestricted funds			
General fund	87,494	40,728	128,222
	<u>87,494</u>	<u>40,728</u>	<u>128,222</u>
TOTAL FUNDS	<u>87,494</u>	<u>40,728</u>	<u>128,222</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	71,326	(30,598)	40,728
	<u>71,326</u>	<u>(30,598)</u>	<u>40,728</u>
TOTAL FUNDS	<u>71,326</u>	<u>(30,598)</u>	<u>40,728</u>

Comparatives for 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>

Comparative 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>

NOTES TO THE FINANCIAL STATEMENTS - continued  
FOR THE YEAR ENDED 31 DECEMBER 2021

9. MOVEMENT IN FUNDS - continued

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

	At 1.1.20 £	Net movement in funds £	At 31.12.21 £
Unrestricted funds			
General fund	85,253	42,969	128,222
	<u>          </u>	<u>          </u>	<u>          </u>
TOTAL FUNDS	<u>85,253</u>	<u>42,969</u>	<u>128,222</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	150,302	(107,333)	42,969
	<u>          </u>	<u>          </u>	<u>          </u>
TOTAL FUNDS	<u>150,302</u>	<u>(107,333)</u>	<u>42,969</u>

10. RELATED PARTY DISCLOSURES

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