

**REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022
FOR
DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK**

Ashdown Hurrey
Chartered Accountant & Business Advisers
20 Havelock Road
Hastings
East Sussex
TN34 1BP

**DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK**

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FOR THE YEAR ENDED 31 DECEMBER 2022**

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**DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK**

**MESSAGE FROM THE CHAIR, LEISA BATKIN
FOR THE YEAR ENDED 31 DECEMBER 2022**

This is the 11th Chair Report that I have had the privilege to present to you. In these unusual times it has been a privilege to support our families and help them to access the right information at the right time, particularly during the pandemic of COVID-19 and in the current pandemic world.

2022 has been a challenging year with the COVID pandemic continuing to dominate the landscape. However, after much careful consideration we were so pleased to be able to hold our annual Family Weekend at PGL Centre In May. It was amazing to catch up with so many of our wonderful families again after being cancelled in both 2020 and 2021. We also welcomed five new families. It is so important for our families and adults to remain connected. Our family weekends are central to creating lasting relationships within our little community.

DBA UK continues to deliver a high quality of care and support to all the members. This is all good news but requires a lot of work behind the scenes. The committee work tirelessly to raise the funds and support the families and people to fundraise. 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, and 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.

One of our big successes for the year was the Aplastic Anaemia Consortium bid which gave other small charities a chance to work together. This consortium will hopefully give us all a bigger platform with a louder voice which could help change and shape policy that determines how we live and the opportunities we may have.

Once again, this charity would not be functioning without the support, dedication, and commitment of its committee and its wonderful volunteers. Without the people stepping forward and giving up their precious time we would not be where we are today.

Thank you to Pete Redmond, Joanne Hubbard, Helen Till and Ellie Hudson.

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 over 20 years ago at the start of the Charity, and we think we have moved rapidly to respond to our family's needs.

On behalf of DBA UK we wish you a full and healthy year and look forward to supporting our community of wonderful families in 2023.

**DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK**

**REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2022**

The trustees present their report with the financial statements of the charity for the year ended 31 December 2022. 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).

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2022

OBJECTIVES AND ACTIVITIES

Significant activities

Thankfully, we were able to hold our annual Family Weekend at Caythorpe Court PGL Centre in May. We had over 80 adults and almost 70 children in attendance.

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. This event was cancelled in 2021 due to Covid. However, this year we agreed with our adults that we should merge the adult conference with our Family Weekend at PGL in May. This worked very well, so much so that this may be a permanent arrangement for future years.

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.

Applications for research funding had almost dried up during the Covid pandemic. However, Dr Norris Igbineweka, of Imperial College London was the successful recipient of a £20K Research Grant this year. We wish him well and look forward to seeing the results from this exciting project in 2023.

Unfortunately, the Annual DBAF International Consensus Conference in Atlanta, USA was postponed again in 2022 as they slowly recover from the aftereffects of the Covid pandemic in 2021. This event brings together DBA specialists, consultants and researchers from all over the world (including the UK) to share knowledge and establish common standards of treatment and management for DBA. DBA UK continue to support this event and hope that it goes ahead in 2023.

Online support through Social Media via our website

Support via social media became even more important during the Covid pandemic in 2021 and as things slowly started to return to normal in 2022. 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.

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2022

ACHIEVEMENT AND PERFORMANCE

We were delighted to be able to organise our Annual Family Weekend at Caythorpe Court PGL centre in Lincolnshire. It was wonderful to see our lovely families and children again as well as welcome five new families into our little community. Everybody had an amazing weekend meeting old friends and new. We had some extremely interesting presentations from our consultants and research partners. We saw record numbers of families attending this year proving that this event is by far the most important event in our calendar.

Throughout the year we also continued 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.

As things slowly started to return to normal, 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, 2022 saw an excellent annual income of £64,409.

Our total expenditure for 2022 was £57,200.

Both income and expenditure were predictably lower than previous years due to ongoing recovery from the Covid pandemic in 2021.

Notable expenditure this year included;

- Dr Norris Igbineweka, Imperial College London - Research Project	£20,000
- Annual DBA UK Family Weekend	£18,174

Total cash assets at 31 December 2022	£136,271
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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.

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2022

STRUCTURE, GOVERNANCE AND MANAGEMENT

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.

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 current 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
Chartered Accountant & Business Advisers
20 Havelock Road
Hastings
East Sussex
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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.

**DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK**

**REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2022**

Approved by order of the board of trustees on 13 October 2023 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 2022.

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
Chartered Accountant & Business Advisers
20 Havelock Road
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18 October 2023

**DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK**

**STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 DECEMBER 2022**

	Notes	31.12.22 Unrestricted fund £	31.12.21 Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies		57,389	68,831
Other trading activities	3	6,749	2,483
Investment income	4	271	12
Total		<u>64,409</u>	<u>71,326</u>
EXPENDITURE ON			
Raising funds		862	305
Other		56,338	30,293
Total		<u>57,200</u>	<u>30,598</u>
NET INCOME		7,209	40,728
RECONCILIATION OF FUNDS			
Total funds brought forward		128,222	87,494
TOTAL FUNDS CARRIED FORWARD		<u><u>135,431</u></u>	<u><u>128,222</u></u>

The notes form part of these financial statements

**DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK**

**BALANCE SHEET
31 DECEMBER 2022**

	Notes	31.12.22 Unrestricted fund £	31.12.21 Total funds £
CURRENT ASSETS			
Cash at bank		136,271	129,062
CREDITORS			
Amounts falling due within one year	8	(840)	(840)
NET CURRENT ASSETS		<u>135,431</u>	<u>128,222</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		135,431	128,222
NET ASSETS		<u>135,431</u>	<u>128,222</u>
FUNDS	9		
Unrestricted funds		<u>135,431</u>	<u>128,222</u>
TOTAL FUNDS		<u>135,431</u>	<u>128,222</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 17 October 2023 and were signed on its behalf by:

P Redmond - Trustee

L Batkin - Trustee

H S Till - Trustee

The notes form part of these financial statements

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022**

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.

**DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK**

**NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 DECEMBER 2022**

3. OTHER TRADING ACTIVITIES

	31.12.22	31.12.21
	£	£
Fundraising events	<u>6,749</u>	<u>2,483</u>

4. INVESTMENT INCOME

	31.12.22	31.12.21
	£	£
Deposit account interest	<u>271</u>	<u>12</u>

5. INDEPENDENT EXAMINERS' REMUNERATION

	31.12.22	31.12.21
	£	£
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 (2021: £5,000). 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 £527 (2021: £190) 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	68,831
Other trading activities	2,483
Investment income	<u>12</u>
Total	<u>71,326</u>
EXPENDITURE ON	
Raising funds	305
Other	<u>30,293</u>
Total	<u>30,598</u>
NET INCOME	40,728
RECONCILIATION OF FUNDS	
Total funds brought forward	87,494

**NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 DECEMBER 2022**

7. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

Unrestricted fund £
<u>128,222</u>

TOTAL FUNDS CARRIED FORWARD

8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.12.22 £	31.12.21 £
Other creditors	<u>840</u>	<u>840</u>

9. MOVEMENT IN FUNDS

	At 1.1.22 £	Net movement in funds £	At 31.12.22 £
Unrestricted funds			
General fund	128,222	7,209	135,431
TOTAL FUNDS	<u>128,222</u>	<u>7,209</u>	<u>135,431</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	64,409	(57,200)	7,209
TOTAL FUNDS	<u>64,409</u>	<u>(57,200)</u>	<u>7,209</u>

Comparatives for 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
TOTAL FUNDS	<u>87,494</u>	<u>40,728</u>	<u>128,222</u>

**NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 DECEMBER 2022**

9. MOVEMENT IN FUNDS - continued

Comparative 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
	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	<u>71,326</u>	<u>(30,598)</u>	<u>40,728</u>

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

	At 1.1.21 £	Net movement in funds £	At 31.12.22 £
Unrestricted funds			
General fund	87,494	47,937	135,431
	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	<u>87,494</u>	<u>47,937</u>	<u>135,431</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	135,735	(87,798)	47,937
	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	<u>135,735</u>	<u>(87,798)</u>	<u>47,937</u>

10. RELATED PARTY DISCLOSURES

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