

REGISTERED CHARITY NUMBER: 1083179

**REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023
FOR
DIAMOND BLACKFAN ANAEMIA SYNDROME SUPPORT GROUP UK**

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

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DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

MESSAGE FROM THE CHAIR, LEISA BATKIN FOR THE YEAR ENDED 31 DECEMBER 2023

This is the 12th Chair Report that I have had the honour to present to you. In a cost-of-living crisis times it has been a privilege to support our families and help them to access the right information at the right time with the additional pressures our families are facing.

2023 has been a challenging year with the financial pressures 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 a privilege to catch up with so many of our wonderful families again. We welcomed new families, and it is so important for our families and adults to remain connected. Our family weekends are central to creating lasting relationships within our community.

DBA UK continues to deliver a high quality of care and support to all the members. 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.

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.

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 2024.

Leisa Batkin

Chair DBA UK

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2023

The trustees present their report with the financial statements of the charity for the year ended 31 December 2023. 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 2023

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 70 adults and almost 60 children in attendance.

Annual Adult Patient Conference

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 in the past couple of years, 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.

This year Professor John Strouboulis of King's College London was successful in applying to us for £30,000 for an exciting 1 year research project on 'GATA 1 short mutations in DBA' the mechanisms by which DBA presents itself. We wish him well and look forward to seeing the results from this exciting project in 2024.

The Annual DBAF International Consensus Conference in Atlanta, USA, took place in October after being postponed since 2019. Our Chair Leisa Batkin and Specialist DBA Haematologist Consultant Dr Deena Iskander attended as representatives of DBA UK. This event is a hugely important to our DBA community of families as it 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 Diamond Blackfan Anaemia. DBA UK continue to support this event and are happy to be part of our international DBA community.

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 and into 2023. 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 2023

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

Total annual Income for 2023 **£78,663**

Total Expenditure for 2023 was **£71,268**

Notable expenditure this year included;

- | | |
|--|---------|
| • Dr John Strouboulis Research Project | £30,000 |
| • Annual DBA UK Family Weekend | £25,522 |

Total Cash Assets at 31 December 2023 **£143,666**

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 2023

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

31 Roman Place
LEEDS
LS8 2DS

Trustees

From 1st January to 31st December (Financial Year)

- | | | |
|----|------------------|--|
| 1. | Leisa Batkin. | Chair and Trustee |
| 2. | Peter Redmond. | Treasurer and Trustee |
| 3. | Ellie Hudson | Secretary and Trustee (appointed as Secretary on 21st May 2023) |
| 4. | Joanne Hubbard | Fundraising Lead and Trustee |
| 5. | Jayson Whittaker | Trustee |
| 6. | Helen Till | Trustee. Resigned as Secretary on 21 st May 2023. Remained as Trustee to 20 th June 2024 |

Independent Examiner

Roseworth Accountancy Ltd.
14 Roseberry Court
Stokesley
Middlesbrough
Nth Yorks
TS9 5QT

PUBLIC BENEFIT

In line with the Charity Commission's guidance on public benefit, the charity committee regularly reviews its objects and achievements in order to ensure that the guidelines are complied with.

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2023

Approved by order of the board of trustees on Tuesday 1st October 2024 and signed on its behalf by:

A handwritten signature in black ink that reads "Peter Redmond". The signature is written in a cursive style with a large, stylized 'P' and 'R'.

Peter Redmond – Treasurer and 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 2023.

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.

Robert J Cooper FMAAT

Roseworth Accountancy Ltd
14 Roseberry Court
Stokesley
Middlesbrough
Nth Yorks
TS9 5QT

27th September 2024

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2023

	Notes	31.12.23 Unrestricted fund £	31.12.22 Unrestricted fund £
INCOME AND ENDOWMENTS FROM			
Donations and legacies		74,262	57,389
Other trading activities	3	2,906	6,749
Investment income	4	1,495	271
Total		78,663	64,409
 EXPENDITURE ON			
Raising funds		830	862
Other		70,438	56,338
Total		71,268	57,200
 NET INCOME		7,395	7,209
 RECONCILIATION OF FUNDS		135,431	128,22
Total funds brought forward			
 TOTAL FUNDS CARRIED FORWARD		142,826	135,431

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

BALANCE SHEET

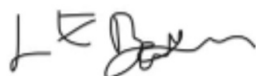
31 DECEMBER 2023

	Notes	31.12.23 Unrestricted fund £	31.12.22 Unrestricted fund £
CURRENT ASSETS			
Cash at bank		143,666	136,271
CREDITORS			
Amounts falling due within one year	8	(840)	(840)
NET CURRENT ASSETS		142,826	135,431
TOTAL ASSETS LESS CURRENT LIABILITIES		142,826	135,431
NET ASSETS		142,826	135,431
FUNDS			
Unrestricted funds	9	142,826	135,431
TOTAL FUNDS		142,826	135,431

The financial statements were approved by the Board of Trustees and authorised for issue on **Tuesday 1st October 2024** and were signed on its behalf by:



Peter Redmond – Treasurer and Trustee



Leisa Batkin – Chair and Trustee



Ellie Hudson – Secretary and Trustee

The notes form part of these financial statements

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2023

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 - FOR THE YEAR ENDED 31 DECEMBER 2023****3. OTHER TRADING ACTIVITIES**

	31.12.23	31.12.22
	£	£
Fundraising events	2,906	6,749

4. INVESTMENT INCOME

	31.12.23	31.12.22
	£	£
Deposit account interest	1,495	271

5. INDEPENDENT EXAMINERS' REMUNERATION

	31.12.23	31.12.22
	£	£
Fees payable to the charity's independent examiners for the independent examination of the charity's financial statements	840	840

6. TRUSTEES' REMUNERATION AND BENEFITS

During the year Trustee; L Batkin was remunerated for consultancy services totalling £3,000 (2022: £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 £1,312 (2022: £527) were paid to one or more Trustees during the year in relation to expenses.

7. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted Fund
	£
INCOME AND ENDOWMENTS FROM	
Donations and legacies 2022	57,389
Other trading activities 2022	6,749
Investment income 2022	271
Total	64,409
Total EXPENDITURE ON	
Raising funds 2022	862
Other 2022	56,338
Total	57,200
NET INCOME	7,209
RECONCILIATION OF FUNDS	
Total funds brought forward	128,222

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK**NOTES TO THE FINANCIAL STATEMENTS – FOR THE YEAR ENDED 31 DECEMBER 2023****7. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued**

		Unrestricted Fund £
TOTAL FUNDS CARRIED FORWARD		135,431

8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.12.23 £	31.12.22 £
Other creditors	840	840

9. MOVEMENT IN FUNDS

	At 1.1.23	Net movement in funds	At 31.12.23
Unrestricted funds			
General fund	135,431	7,395	142,826
TOTAL FUNDS	135,341	7,395	142,826

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

	Incoming Resources £	Resources expended £	Movement in Funds £
Unrestricted funds			
General fund	78,663	(71,268)	7,395
TOTAL FUNDS	78,663	(71,268)	7,395

Comparatives for 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	128,222	7,209	135,431

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK**NOTES TO THE FINANCIAL STATEMENTS - FOR THE YEAR ENDED 31 DECEMBER 2023****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	64,409	(57,200)	7,209
TOTAL FUNDS	64,409	(57,200)	7,209

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

	At 1.1.22 £	Net movement in funds £	At 31.12.23 £
Comparatives for movement in funds			
Unrestricted funds			
General fund	128,222	14,604	142,826
TOTAL FUNDS	128,222	14,604	142,826

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	143,072	(128,468)	14,604
TOTAL FUNDS	143,072	(128,468)	14,604

10. RELATED PARTY DISCLOSURES

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