

REGISTERED CHARITY NUMBER: 1083179

**REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2024
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 2024

As Chair of DBAS UK, it is my privilege to present this, my 13th Annual Report, reflecting on our activities, achievements, and challenges over the past year. DBAS UK remains dedicated to supporting individuals and families affected by Diamond Blackfan Anaemia Syndrome, a rare genetic disorder. Our mission is to provide support, fund research, and foster a sense of community among those impacted by DBAS.

This year, we have continued to strengthen our support network, bringing together families and individuals affected by DBAS. Our annual conference was a significant success, providing a platform for patients, families, and medical professionals to share experiences, access the latest medical information, and offer mutual support. The conference also featured workshops and sessions led by experts in the field, enhancing our community's knowledge and resilience.

DBAS UK has been at the forefront of funding innovative research projects aimed at improving treatments and finding a cure for DBAS. We have successfully supported a UK patient registry, which serves as a central resource for doctors and researchers. This registry is crucial for documenting each case, facilitating better care, and opening new avenues for research. Additionally, we have made significant progress in developing a patient friendly Standard of Care document for both children and adults to ensure consistent and high-quality treatment for all DBAS patients nationwide.

Our fundraising efforts have been instrumental in supporting our initiatives. We are grateful for the generosity of our supporters, whose contributions have enabled us to fund vital research projects and provide essential resources to families.

In the coming year, we will continue to strengthen our research collaborations, both nationally and internationally. By partnering with leading research institutions and medical professionals, we aim to accelerate the development of new treatments and move closer to finding optimal treatment choices for DBAS.

Our focus on community outreach and education will remain a priority. We will work to increase awareness of DBAS, promote early diagnosis, and advocate for better healthcare policies. Through workshops, informational sessions, and community events, we will continue to build a strong, informed, and supportive DBAS community.

I am so proud of the progress we have made this year and the resilience of our community. The achievements of DBAS UK are a testament to the dedication and hard work of our volunteers, supporters, and partners. As we look to the future, we remain committed to our mission of providing support, funding research, and fostering a sense of community among those affected by Diamond Blackfan Anaemia Syndrome.

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

Thank you for your continued support.

Leisa Batkin

Chair and Trustee DBA UK

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

REPORT OF THE TRUSTEES

FOR THE YEAR ENDED 31 DECEMBER 2024

The trustees present their report with the financial statements of the charity for the year ended 31 December 2024. 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 Syndrome (DBAS) and associated conditions.
- b) To educate the general public through promotion of research and the dissemination of knowledge about Diamond Blackfan Anaemia Syndrome (DBAS).

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2024

OBJECTIVES AND ACTIVITIES

Significant activities

In May we held our annual Family Weekend at PGL Caythorpe Court in Lincolnshire. As always, it was wonderful to see many of our regular families again, as well as welcoming several new families into our amazing support network. The weekend provides a safe space where parents and adults can share experiences and knowledge, listen to a wide range of professionals and consultants giving amazing presentations and talks. All this happens while the children are taken away, enjoying themselves on high wires, ziplines climbing walls. This year we had over seventy adults and 60 children attend. The weekend is always the highlight of our calendar. DBSA UK cover all costs for the weekend at no cost at all to our families.

Annual Adult Patient Conference

In previous years, each year we held a separate conference for our small number of adult DBAS patients at a different time and location. However, in the past couple of years we have merged this event into our regular Family Weekend in May. This has proved very popular for both our adults and other parents. As a result, we have decided to continue with this arrangement as a regular plan.

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, we have collaborated with the DBAF Foundation in the USA on two projects relating to research for the mechanisms, causes and treatment of DBAS.

In January 2024 DBAS UK contributed \$15,000 USD (£12,097) towards a Research Project Competition organised and managed by the DBAF Foundation USA. The competition is open to researchers and scientists from all over the world, submitting applications for DBAS specific research projects. DBAS UK are proud to support this amazing initiative.

In March, again DBAS UK were happy to support a joint funding venture with DBAF Foundation USA to fund a researcher for one year under the guidance of Dr Deena Iskander at Imperial College London. DBAF USA contributed \$40,000 USD (£35,160) and we, DBAS UK contributed £30,000 to provide the requested £65,160 to fund the project.

The Global Bridges DBAS Conference was held in Madrid in May. This is an amazing conference, bringing together specialists, clinicians, consultants and researchers in DBAS from almost all European countries. Leisa Batkin, our charity Chair attended and returned filled with hope that so many wonderfully clever people are focussed on finding the mechanisms, causes and treatments for such a rare condition as DBAS. DBAS UK were happy to contribute 6,000 Euros (£5,280) towards the huge cost of organising and hosting the weekend conference.

Online support through social media via our website

Our Facebook pages and Instagram reels continue to be an invaluable source of information, support and inspiration for all our DBAS patients and families. We also have a website which is packed with information relating to DBAS. This year our website has had a complete makeover. It previously felt and looked a little outdated. We reviewed all content and are now happy that it's look and feel is modern and user friendly. Additionally, we ensured that it is fully functional on mobile devices like phones and tablets.

Telephone Helpline

DBAS UK continue to provide a telephone helpline for DBAS 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

DBAS 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 DBAS treatment and management.

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 DECEMBER 2024

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 have felt supported and connected. It was really important that we offered guidance that was up to date, relevant and easy to understand.

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 2024 **£70,635**

Total Expenditure for 2024 was **£86,584**

Notable expenditure this year included;

- | | |
|---|---------|
| • Shared Grant with DBAF USA for Collaboration Research Competition | £12,097 |
| • Shared Grant with DBAF USA for Dr Deena Iskander Research Project | £30,000 |
| • Annual DBA UK Family Weekend | £24,069 |
| • Global Bridges Event contribution (6,000 Euros) | £ 5,280 |

Total Cash Assets at 31 December 2024 **£127,717**

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 2024

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 2024) |
| 4. Joanne Hubbard | Fundraising Lead and Trustee |
| 5. Jayson Whittaker | Trustee |
| 6. Helen Till | Trustee. Resigned as Trustee to 20 th June 2024 |

Independent Examiner for 2024

Wasley Chapman LLP
5 Bobbies Bank
Whitby
North Yorkshire
YO21 1EF
Tel. 01947 605921
Contact: Ross Meadows

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 2024**

Approved by order of the board of trustees on 16th October 2025 and signed on its behalf by:

A handwritten signature in black ink, reading "Peter Redmond". The signature is written in a cursive, flowing style.

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 2024.

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.



Ross Meadows
Wasley Chapman LLP

5 Bobbies Bank
Whitby
North Yorkshire
YO21 1EF
Tel. 01947 605921

16th October 2025

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2024

	Notes	31.12.24 Unrestricted fund £	31.12.23 Unrestricted fund £
INCOME AND ENDOWMENTS FROM			
Donations and legacies		68,415	74,262
Other trading activities	3	519	2,906
Investment income	4	1,701	1,495
Total		70,635	78,663
 EXPENDITURE ON			
Raising funds		840	830
Other		85,744	70,438
Total		86,584	71,268
 NET INCOME		-15,949	7,395
 RECONCILIATION OF FUNDS		142,826	135,431
Total funds brought forward			
 TOTAL FUNDS CARRIED FORWARD		126,877	142,826

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

BALANCE SHEET

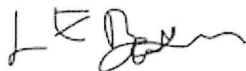
31 DECEMBER 2024

	Notes	31.12.24 Unrestricted fund £	31.12.23 Unrestricted fund £
CURRENT ASSETS			
Cash at bank		127,717	143,666
CREDITORS			
Amounts falling due within one year	8	(840)	(830)
NET CURRENT ASSETS		126,877	142,826
TOTAL ASSETS LESS CURRENT LIABILITIES		126,877	142,826
NET ASSETS		126,877	142,826
FUNDS			
Unrestricted funds	9	126,877	142,826
TOTAL FUNDS		126,877	142,826

The financial statements were approved by the Board of Trustees and authorised for issue on **16th October 2025** 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 2024

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 2024****3. OTHER TRADING ACTIVITIES**

	31.12.24	31.12.23
	£	£
Fundraising events	519	2,906

4. INVESTMENT INCOME

	31.12.24	31.12.23
	£	£
Deposit account interest	1,701	1,495

5. INDEPENDENT EXAMINERS' REMUNERATION

	31.12.24	31.12.23
	£	£
Fees payable to the charity's independent examiners for the independent examination of the charity's financial statements	840	830

6. TRUSTEES' REMUNERATION AND BENEFITS

During the year Trustee; L Batkin was remunerated for consultancy services totalling £3,000 (2023: £3,000). 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 £366 (2023: £1,312) 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 2023	74,262
Other trading activities 2023	2,906
Investment income 2023	1,495
Total	78,663
Total EXPENDITURE ON	
Raising funds 2023	0
Other 2023	71,268
Total	71,268
NET INCOME	7,395
RECONCILIATION OF FUNDS	
Total funds brought forward	135,431

Continued ...

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

NOTES TO THE FINANCIAL STATEMENTS – FOR THE YEAR ENDED 31 DECEMBER 2024

7. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

		Unrestricted Fund £
TOTAL FUNDS CARRIED FORWARD		142,826

8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.12.24 £	31.12.23 £
Other creditors	840	830

9. MOVEMENT IN FUNDS

	At 1.1.24	Net movement in funds	At 31.12.24
Unrestricted funds			
General fund	142,826	-15,949	126,877
TOTAL FUNDS	142,826	-15,949	126,877

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

	Incoming Resources £	Resources expended £	Movement in Funds £
Unrestricted funds			
General fund	70,635	(85,744)	-15,949
TOTAL FUNDS	70,635	(85,744)	-15,949

Comparatives for 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	135,431	7,395	142,826

NOTES TO THE FINANCIAL STATEMENTS - FOR THE YEAR ENDED 31 DECEMBER 2024

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	68,663	(71,268)	7,395
TOTAL FUNDS	78,663	(71,268)	7,395

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

	At 1.1.23 £	Net movement in funds £	At 31.12.24 £
Comparatives for movement in funds			
Unrestricted funds			
General fund	142,826	-15,949	126,877
TOTAL FUNDS	142,826	-15,949	126,877

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.