

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

England & Wales · Charity number 1083179

Details

Other names DBA SUPPORT GROUP UK, DBA UK

Status Registered

Legal form Other

Registered 2000-11-02

Register [View on the Charity Commission register](#)

Contact

Address 31 Roman Place
Leeds
LS8 2DS

Phone 07797841489

Email info@diamondblackfan.org.uk

Website <http://www.diamondblackfan.org.uk>

Activities

Objects: 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).

Activities: Provide support to families affected by Diamond Blackfan Anaemia. Provide information and education on the condition.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities

Geography

- **Area of benefit:** NOT DEFINED. IN PRACTICE ENGLAND AND WALES, SCOTLAND AND NORTHERN IRELAND
- Northern Ireland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£70,635	£86,584	-	-
2023-12-31	£78,663	£71,268	-	-
2022-12-31	£64,409	£57,200	-	-
2021-12-31	£71,326	£30,598	-	-
2020-12-31	£78,976	£76,735	-	-

Trustees

Name	Role	Appointed
Leisa Batkin	Chair	2014-02-05
Eleanor May Hudson		2023-05-21
Jayson Whitaker		
Joanne Hubbard		2016-05-22
Peter Redmond		2014-02-05

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

England & Wales - Charity number 1083179

Accounts

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:



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

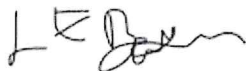
31 DECEMBER 2024

	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

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:

Comparatives for movement in funds	At 1.1.23 £	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

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.

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

England & Wales - Charity number 1083179

Accounts

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 initial 'P'.

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**

		31.12.23 Unrestricted fund £	31.12.22 Unrestricted fund £
INCOME AND ENDOWMENTS FROM	Notes		
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**

TOTAL FUNDS CARRIED FORWARD		Unrestricted Fund £
		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:

Comparatives for movement in funds	At 1.1.22 £	Net movement in funds £	At 31.12.23 £
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.

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

England & Wales - Charity number 1083179

Accounts

**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**

**CONTENTS OF THE FINANCIAL STATEMENTS
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

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
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.

**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
Hastings
East Sussex
TN34 1BP

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

**DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK**

**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 year 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	6,749	2,483
	<u>6,749</u>	<u>2,483</u>

4. INVESTMENT INCOME

	31.12.22	31.12.21
	£	£
Deposit account interest	271	12
	<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	840	840
	<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	12
Total	<u>71,326</u>
EXPENDITURE ON	
Raising funds	305
Other	30,293
Total	<u>30,598</u>
NET INCOME	40,728
RECONCILIATION OF FUNDS	
Total funds brought forward	87,494

**DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK**

**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
	<u>128,222</u>	<u>7,209</u>	<u>135,431</u>
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
	<u>64,409</u>	<u>(57,200)</u>	<u>7,209</u>
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
	<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>

**DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK**

**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
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
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
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.

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

England & Wales - Charity number 1083179

Accounts

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

CONTENTS OF THE FINANCIAL STATEMENTS
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 reflect 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
---------------------------------------	----------

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

	Notes	31.12.21 Unrestricted fund £	31.12.20 Total funds £
INCOME AND ENDOWMENTS FROM			
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>

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.

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK

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	
2,483	8,532
<u>2,483</u>	<u>8,532</u>

4. INVESTMENT INCOME

31.12.21	31.12.20
£	£
Deposit account interest	
12	84
<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	
840	840
<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 £
INCOME AND ENDOWMENTS FROM	
Donations and legacies	70,360
Other trading activities	8,532
Investment income	84
Total	<u>78,976</u>
EXPENDITURE ON	
Raising funds	1,006
Other	<u>75,729</u>
Total	<u>76,735</u>
NET INCOME	2,241
RECONCILIATION OF FUNDS	
Total funds brought forward	85,253
TOTAL FUNDS CARRIED FORWARD	<u><u>87,494</u></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	840	840

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
TOTAL FUNDS	87,494	40,728	128,222

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
TOTAL FUNDS	71,326	(30,598)	40,728

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
TOTAL FUNDS	85,253	2,241	87,494

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
TOTAL FUNDS	78,976	(76,735)	2,241

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.

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP UK

England & Wales - Charity number 1083179

Accounts

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

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

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FOR THE YEAR ENDED 31 DECEMBER 2020

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

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

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

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

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

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2020

The trustees present their report with the financial statements of the charity for the year ended 31 December 2020. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

- a) For the relief of sickness of those suffering either directly or indirectly from Diamond Blackfan Anaemia (DBA) and associated conditions.
- b) To educate the general public through promotion of research and the dissemination of knowledge about Diamond Blackfan Anaemia (DBA).

Significant activities

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

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

Annual Adult Patient Conference

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

Support of DBA Research and improved clinical management techniques.

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

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

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

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

Online support through Social Media via our website

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

Telephone Helpline

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

Information Leaflets

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

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2020

ACHIEVEMENT AND PERFORMANCE

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

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

Our total expenditure 2020 was £76,735

Notable expenditure included;

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

Total cash assets at 31 December 2020 £88,334

Reserves policy

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

FUTURE FUNDRAISING OBJECTIVES AND PLANS

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

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

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

Recruitment and appointment of new trustees

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

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

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 DECEMBER 2020

STRUCTURE, GOVERNANCE AND MANAGEMENT

Committee Roles and Responsibilities

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

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

Risk management

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

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number
1083179

Principal address

71-73 Main Street
Palterton
Chesterfield
Derbyshire
S44 6UR

Trustees

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

Independent Examiner

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

PUBLIC BENEFIT

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

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

P Redmond - Trustee

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

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

Responsibilities and basis of report

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

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

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

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

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

29 October 2021

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 DECEMBER 2020

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

DIAMOND BLACKFAN ANAEMIA SUPPORT GROUP
UK

BALANCE SHEET
31 DECEMBER 2020

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

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

P Redmond - Trustee

L Batkin - Trustee

H S Till - Trustee

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

1. STATUTORY INFORMATION

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

2. ACCOUNTING POLICIES

Basis of preparing the financial statements

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

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

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

Income

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

Expenditure

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

Taxation

The charity is exempt from tax on its charitable activities.

Fund accounting

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

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

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

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

3. OTHER TRADING ACTIVITIES

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

4. INVESTMENT INCOME

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

5. INDEPENDENT EXAMINERS' REMUNERATION

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

6. TRUSTEES' REMUNERATION AND BENEFITS

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

Trustees' expenses

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

7. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

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

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

8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

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

9. MOVEMENT IN FUNDS

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

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

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

Comparatives for movement in funds

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

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

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

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

9. MOVEMENT IN FUNDS - continued

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

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

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

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

10. RELATED PARTY DISCLOSURES

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