

Annual Report & Financial Statements

Haemophilia & Bleeding Disorders Counselling Association
As at 31 March 2025

Prepared by A-Counting Genie Ltd

Contents

Administrative details	3
Trustee's Report	10
Directors Report	46
Independent Examiners report	53
Balance Sheet	55
Notes to the Financial Statements	56
Movements in Equity	58
Profit and Loss	59

Structure, Governance and Management

Description of charity's trusts:	
Type of governing document	Constitution
How is the charity constituted?	Charitable Incorporated Organisation
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Election to post

Additional information

HBDCA Organisational Structure

Trustees

Nina Beer

Governance and Fundraising

Joseph Peaty

Patient expert: Inhibitors and Infected Blood

Cynthia Creavalle

Finance

Dr Kate Khair

Medical expertise

Maryam Samina

Patient expert: Ultra-rare community

Farid Gasanov

Finance and Charity expertise

Ambassador - Ros Cooper

Women with bleeding disorders and Infected Blood

HBDCA Team

Founder and Director

Christina Burgess
Strategy and Infected Blood Lead

Senior Associates

Lisa Fowler
Deputy Director – Governance Lead

Marion MacGillivray
Healthcare Professionals Lead

Angela Johnson
Safeguarding Lead

Anila Babla
Communications and Complementary Therapies Lead

Clare Nield
Crisis and Women with Bleeding Disorders Lead

Associates

Alicia Fowkes
Psychotherapist

Jennifer Wainman
Psychotherapist

Eve Jones
Psychotherapist/Art psychotherapist

Helen O'Mahony
Psychotherapist

Dr. Hannah Dunford
Child Psychologist

Patrick Browne
Associate Music Therapist

Aizat Aidarbekova
Interpreter (Kyrgyzstan)

<p>The charity's organisational structure and any wider network with which the charity works</p>	<p>HBDCa is led by six trustees: the Chair, Nina Beer, along with Joseph Peaty, Dr Kate Khair, Farid Gasanov, Maryam Samina and Cynthia Creavalle. HBDCa also has a wonderful ambassador, Ros Cooper.</p> <p>Trustee Meetings were held on:</p> <p>26 July, 2024 15 September, 2024 10 December, 2024 (re Infected Blood) 27 January, 2025 24 March, 2025 (AGM)</p> <p>The day to day running of the charity and its strategic direction is led by its Founder and Director, Christina Burgess, with essential input from the trustees. Insight which is used to inform HBDCa's work and focus, is also contributed to by the ten-fold psychotherapeutic team and by the bleeding disorder community itself.</p> <p>HBDCa has worked closely with the Haemophilia Departments at the Royal London Hospital, the Kent and Canterbury Hospital, Birmingham, University Hospital Southampton and Oxford to provide psychological support to their patients, including family members. As well as on an ad hoc basis for St George's Tooting and other Haemophilia Centres.</p> <p>HBDCa also provides psychological support to the Infected Blood community affected by HIV or co-infected with HIV/Hepatitis C through the Terrence Higgins Trust counselling service and also to anyone infected either with HIV, Hepatitis C or co-infected with HIV/Hepatitis C through</p>
--	--

	England Infected Blood Support Scheme (EIBSS).
Relationship with any related parties	<p>HBDCA is an approved provider of psychological support for the Royal London Haemophilia Department, the Kent and Canterbury Haemophilia Department, Birmingham Haemophilia Centre, Oxford Haemophilia Centre, University Hospital Southampton Haemophilia Centre, the Terrence Higgins Trust Counselling Service and EIBSS. It collaborates with The UK Haemophilia Society, Haemosexual, the HPA, Haemnet, the Hepatitis C Trust and the Kyrgyz NMO (National Member Organisation). On a European level it also collaborates with EAHAD and with the EHC.</p>
Other	<p>The UK Haemophilia Society and HBDCA are in the process of formulating a Memorandum of Understanding between the two organisations with the certainty that there will be greater collaboration in the coming years especially around Infected Blood, Rare Disorders and Gene Therapy.</p> <p>Having a collaborative approach continues to enable HBDCA not only to contribute to improved quality of life for people with a bleeding disorder but also to enable the HBDCA team to continue to learn, and, therefore, maintain, up-to-date knowledge and insight into the ever changing, fast-moving landscape of medical care and provision this community is currently experiencing.</p> <p>These new landscapes all require psychosocial provision to create a sense of stability for the bleeding disorder community in these changing environments. Also, it is hugely important that HBDCA continues to provide high quality psychotherapy,</p>

	along with peer support from a trusted source, to the Infected Blood community during such challenging times for them ahead – especially in the next few years.
--	---

Reference and Administrative details

Charity name	HBDCA
Other name the charity uses	(Haemophilia and Bleeding Disorders Counselling Association)
Registered charity number	1191416
Charity's principal address	<p>Current address since 31 March, 2021</p> <p>5, St Andrews House St Andrews Park Soham, Ely CB7 5GY</p> <p>Previous address:</p> <p>3, St Matthews Gardens Cambridge CB1 2PH</p>

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Nina Janine Beer	Chair		
2	Joseph Peaty			
3	Cynthia Creavalle			
4	Dr Kate Khair			
5	Farid Gasanov			
6	Maryam Samina			
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

Name of chief executive or names of senior staff members (Optional information)

Christina Burgess

Exemptions from disclosure

Reason for non-disclosure of key personnel details

N/A

HBDCa Trustees' Annual Report

For the period: 1 April, 2024 To 31 March, 2025

Charity name: **HBDCa**
(Haemophilia and Bleeding Disorders Counselling Association)

Charity registration number: 1191416

Objectives and Activities

Summary of the purposes of the charity as set out in its governing document	<p>To promote and protect the physical and mental health of people in the UK affected by a bleeding disorder, their families and carers through:</p> <p>A) The provision of counselling and therapy;</p> <p>B) Providing workshops, support and signposting.</p> <p>C) Raising awareness of the need for support for people affected by a bleeding disorder.</p> <p>D) Providing workshops to professionals to provide insight and improve the support they provide to the bleeding disorder community.</p>
HBDCa Strategic Overview	<p>During 2024 – 2025 there were many challenges for HBDCa.</p> <p>One of the major challenges was the impending Infected Blood Final Report publication on 20 May, 2024, and how that might affect the infected blood community. HBDCa needed to ensure that it stepped up to the mark with psychotherapeutic and psychosocial provision during this momentous time. Fortunately, HBDCa had been anticipating the additional pull on its resources and had spent time in preparing the team and putting plans in place to ensure it had capacity.</p>

	<p>There was also an increased call on HBDCA's resources during this year through being invited by NHS England to be a stakeholder member of their IBPS (Infected Blood Psychology Service) working group whose purpose was to help inform and shape the new service. Time, expertise and insight was given freely by HBDCA despite no funding being offered by the government or by NHS England for this expertise.</p> <p>In addition, HBDCA was concerned that funding might be withdrawn during this period by EIBSS (England Infected Blood Support Service) whose clientele HBDCA has been providing psychotherapeutic support to for several years due to Infected Blood support services being re-aligned post the Final Report. At present this has not materialised and HBDCA continues to support EIBSS clientele.</p> <p>A major concern was also that as the IBPS rolled out across the UK, some Centres currently being supported by HBDCA would avail themselves exclusively of this NHS England funded service. However, those concerns have been allayed, and this has only happened with one Centre, the Kent and Canterbury. Other Centres wish to maintain HBDCA's presence as an essential component of their MDT (multi-disciplinary team) and, even should they have been assigned an IBPS psychologist, they have wanted existing patients to remain under the care of HBDCA.</p> <p>As always, HBDCA is aware that any reduction in funding will reduce its ability to provide expert, psychotherapeutic support to the bleeding disorder community so it continues to explore additional channels of funding to address this. It anticipates that in the next Trustees' Report in 2025 – 2026, there will be confirmation of further funding channels.</p> <p>HBDCA continues to focus on all cohorts equally and to ensure that the HBDCA psychotherapeutic team has all the tools it needs to enable them to carry out these vital services.</p> <p>HBDCA, in the coming year, hopes that the Infected Blood community is afforded the justice and compensation each one of its members so deserves and finds, finally, a sense of equilibrium still so absent for so many at present. HBDCA hopes that, in no</p>
--	--

	<p>small way, our support, has helped sustain this community during these immensely challenging times.</p> <p>HBDCA also aims to ensure that we sustain all cohorts with that same level of care: newly diagnosed families, women with rare and ultra-rare bleeding disorders, patients undergoing Gene Therapy, those with inhibitors, the ageing community and people experiencing long-term chronic pain.</p> <p>The bleeding disorder community still experiences many psychological and psychosocial challenges. HBDCA aims at all times to rise to the challenge of supporting this incredible community. It hopes to do this by good financial housekeeping practices, by an increased awareness by others of HBDCA's expertise and also by its growing reputation as a key provider of psychotherapeutic support.</p>
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	<p>The Royal London Hospital Haemophilia Department (RLH)</p> <p>Throughout this period, HBDCA continued to support patients and family members at the Royal London Hospital Haemophilia Department (RLH) with the 5-year contract having been signed and agreed in August, 2023. The current contract includes funding for a part-time child psychologist who has now commenced supporting 2 paediatric patients.</p> <p>The support provided during 2024 – 2025 by HBDCA consisted of one-to-one psychotherapeutic counselling, themed wellbeing events, and the facilitation of a monthly peer support group for male adults with a bleeding disorder and facilitation of a monthly peer support group for women with bleeding disorders. 4 women with rare bleeding disorders from the RLH have also participated throughout this year in the monthly Ultra-Rare Peer Support Group which HBDCA facilitates on a voluntary basis. There are now 11</p>

	<p>members of this group from across the UK.</p> <p>HBDCA has been supporting 45 patients during this period. Approximately 60 contact calls were made during this period, 10 pre-assessment sessions carried out and 400 psychotherapy one-to-one sessions completed.</p> <p>The number of patients currently being supported equates to more than 60% of those patients originally referred to HBDCA by the RLH.</p> <p>Any of the patients who had been referred but felt they did not require psychological support at this stage were also made aware that they could reach out for support to HBDCA at any time. They were also notified about peer support groups they might join and wellbeing events they might attend.</p> <p>Three wellbeing days were scheduled to take place:</p> <ul style="list-style-type: none"> • Newly Diagnosed Families • Infected Blood • Gene Therapy. <p>The Newly Diagnosed wellbeing day was postponed but will take place February, 2026.</p> <p>The Gene Therapy Wellbeing event is further delayed until the Haemophilia Department feels it is the right time for them to commence this new therapy first. It is anticipated this wellbeing event will now take place in 2026. However, separately to this, HBDCA plans to commence a Gene Therapy Peer Support Group in early 2026.</p>
--	---

	<p>HBDCa facilitated a wellbeing event for the Infected Blood community in August, 2024, post the Infected Blood Final Report that May. It was offered to those Infected and Affected. The location was a Royal London site away from the main hospital.</p> <p>Christina Burgess, representing HBDCa, also participated, in October, 2024, in a VWD (Von Willebrand Disease) event at the Royal London, where she interviewed one of HBDCa's clients about the psychological and psychosocial impact of living with VWD. Impact statements were read out from HBDCa Ambassador, Ros Cooper, and long-term HBDCa supporter, Sam Nield, on the psychological impacts of living with VWD. The event, which was very well received and attended, was also attended by HBDCa Trustee, Dr. Kate Khair.</p> <p>HBDCa now facilitates all its wellbeing events in person at the Royal London. This had not been possible until recently whilst the Haemophilia Centre had still restricted visits to the Centre in person post the Covid-19 pandemic.</p> <p>HBDCa continues to hold valuable conversations with the RLH in order to develop collaborations between the Haemophilia Department and the Obstetrics/Gynaecology Departments at the Royal London in order that HBDCa can support, psychologically, when needed, young women with bleeding disorders who might be considering pregnancy, are pregnant, have experienced fertility issues, or are now post-natal.</p> <p>Continuing and new themes identified during psychotherapy sessions:</p>
--	--

	<ul style="list-style-type: none"> • Impact on women who have experienced issues when contemplating starting a family, whether this be infertility, miscarriage or judgement from relatives and family members. • A heightened sense of isolation for women in the ultra-rare cohort is a common experience. Another common story is of difficulty getting diagnosed. • Invisible – patients can sometimes feel that they are invisible or not listened to. Sometimes this is a symptom of their psychological state with this sense of invisibility reducing as they acknowledge and appreciate that they are finally being heard. • Loss and adjustments to a new sense of self and identity - due possibly to a patient accessing novel therapies and having to reassess their lives and sense of self. • This has also been identified for some patients being supported by HBDCA in the Infected Blood cohort. Some people feel a sense of loss now that the Public Inquiry has concluded and now that they no longer need to campaign so strongly. • Patient empowerment, more specifically having a deeper understanding of their bleeding disorder and treatment plans. • Importance of patient autonomy. • Death anxiety - Having a chronic condition in the family tends to increase fears related to dying.
--	--

	<ul style="list-style-type: none"> • Limiting beliefs - Clearly having a physical disability may limit some activities however it has been noticed that it may be accompanied by limiting beliefs in one's own potential which are self-imposed. • Learned helplessness/entitlement - When dependent on public health services and/or financial support in part it can lead to a phenomenon of helplessness and even entitlement. Counselling can help clients to feel empowered. • Patients often speak more about current personal issues, family dynamics than their disorder. • It is helpful to have somewhere to say exactly how they feel as they do not want to share/burden others with these thoughts. • The Infected Blood situation continues to greatly impact patients and family members. There is a great level of uncertainty for this community and re-triggering of trauma post the Infected Blood Final Report. Some patients not previously involved in Infected Blood have begun to question whether they might have been given infected blood without their knowledge and have been left feeling very unsure about their own situations. HBDCA has had to reassure patients and also pass on these concerns to the Royal London for them to respond.
--	---

Quote from a patient being supported by HBDCA:

'Your organisation and my psychotherapist, Lisa, has done more for me than I can ever offer or do in return'.

The Kent and Canterbury Hospital Haemophilia Department (K&C)

Having been providing a similar level of psychological support to K&C patients to that for the Royal London, due to K&C accepting funding in 2025 from NHS England for an Infected Blood Psychologist from the newly created IBPS (Infected Blood Psychology Service), HBDCA was notified that its contract would come to a conclusion in June, 2025. However, following a further conversation with the K&C, it was agreed that HBDCA could continue to support patients for three to four months after that. The reason for this was that the K&C Haemophilia Department accepted that it had not consulted patients about this impactful change and had also not taken into consideration that it would be very detrimental to patients' mental wellbeing for them to be removed at short notice from their trusted HBDCA psychotherapists who had been supporting them on a long-term basis. It was agreed that HBDCA would, instead, work towards a tailored conclusion for each patient over a period of months in order that they then might transition much more smoothly, should they continue to require support, to the new psychologist in post. This psychologist will supplement their Infected Blood work with general bleeding disorder support. It was agreed by the K&C and HBDCA that all efforts would now be made to manage this situation for

	<p>patients with the best outcome. There will be patients who may decide they would prefer to remain with HBDCA. A decision will be made later in 2025/early 2026 as to how HBDCA might continue to support them.</p> <p>During this time, HBDCA carried out 50 contact calls with patients/family members referred by the MDT, 6 pre-assessment sessions and provided 150 psychotherapeutic sessions to 18 patients accessing support.</p> <p>Quote from K&C patient:</p> <p><i>'The sessions with Clare provide invaluable support for every aspect of my life. As much as this was initially about support with me coping with my son's condition, it has supported me in so many ways.</i></p> <p><i>Clare has been able to reassure me when I have spoken to her about the challenges of his condition, from managing his treatment to the guilt I still feel around him inheriting the condition from me.</i></p> <p><i>This year has been very challenging for myself and my family including coping with a self-referral for Autism. Clare has been able to talk through these aspects of my life and coached me through some of the challenges I have had with it.</i></p> <p><i>My younger son was diagnosed with ADHD back in April and my older son has been recently diagnosed with Autism. Clare has helped me to navigate these diagnoses. This has helped me to settle and accept this recent news.</i></p> <p><i>Clare is extremely approachable and empathetic. I feel comfortable enough that I have been able to release my emotions, enabling me to move forward.</i></p>
--	---

	<p><i>It is providing me with much needed support that I have needed for years. I had reservations from my previous experiences 15 years ago, however I am really pleased and grateful that the opportunity has been offered to me and I hope this statement reaffirms how appreciative I am for all the support I have currently received from Clare and HBDCA.'</i></p> <p>As with the RLH, any patients who decided they did not require psychotherapeutic support were notified that they could access this support at any time in the future. They were also notified of any relevant peer support groups commencing or any relevant, themed wellbeing workshops.</p> <p>HBDCA ran an Infected Blood wellbeing event on 24 May, 2024. It was very well attended and well-received.</p> <p>Two patients at the K&C are members of the HBDCA Ultra-Rare Peer Support Group.</p> <p>HBDCA continues to support a couple with joint psychotherapy due to their unique circumstances.</p> <p>N.B. As well as providing one-to-one psychotherapy, HBDCA has continued to carry out regular check-in calls and in-person meetings with a small cohort of patients from the RLH and the K&C, who require this, including the couple noted in this report, due to their circumstances and issues which have imposed greater isolation on them all compared to most in the bleeding disorder community.</p> <p>Support beyond One-to-One Therapy</p> <p>In addition to individual psychotherapeutic support, taking into</p>
--	--

	<p>account peer support groups and wellbeing events held this year, including Infected Blood events, HBDCA has supported, additionally, more than 250 people, including parents, children, siblings, grandparents and partners from across all cohorts within the bleeding disorder community.</p> <p>Oxford University Hospital Haemophilia Centre</p> <p>HBDCA commenced supporting patients and family members at Oxford in early 2024 for a one-year pilot. Despite funding issues, post the one-year pilot, the Haemophilia Centre has continued to fund HBDCA to support its patients and is actively seeking funding to enable HBDCA to remain at the Centre for the long-term.</p> <p>HBDCA has facilitated two Infected Blood events for the Oxford Haemophilia Centre, during this time. 11 June, 2024, with co-facilitation by Joseph Peaty and Ros Cooper, alongside Christina Burgess. The second Infected Blood event was held on Friday, 28 February, 2025. It was co-facilitated by key Infected Blood campaigner, Andrew Evans, again alongside Christina Burgess. Both events were well-attended and well-received. HBDCA has also demonstrated a collaborative approach to working with the newly in-post IBPS psychologist at Oxford and it is anticipated that a further, joint Infected Blood event will take place in 2026.</p> <p>Quote from Oxford patient:</p> <p><i>'You and your team have rare and golden caring qualities and are like angels. Amazing!'</i></p>
--	--

**University Hospital Southampton
Haemophilia Centre**

HBDCA has been contracted for 2 years, commencing in February, 2025, to support patients at the UHS. Included in this support will be two wellbeing events as well as access by patients and family members to virtual peer support group meetings facilitated by HBDCA, including for Ultra-rare and for Infected Blood. It is anticipated that up to 10 patients will be supported each year during this period.

On 28 March, 2025, HBDCA facilitated an Infected Blood event for patients and family members at UHS. It was well attended.

HBDCA is planning to facilitate a wellbeing event for Women with Bleeding Disorders in the near future.

**St George's Hospital, Tooting,
Haemophilia Department**

Despite not having a formal agreement with the Haemophilia Department at St George's, Tooting, with whom HBDCA has worked informally for the past 3 years, HBDCA continues to support patients there on an ad hoc basis, including providing letters for patients in order for them to apply for funding from the England Infected Blood Support Scheme (EIBSS).

Through HBDCA's work with St George's, it now provides psychotherapeutic support to its first ITP (Immune Thrombocytopenia) patient. HBDCA hopes to support further clients in this cohort in the near future.

	<p>Hammersmith Haemophilia Department - Imperial College Healthcare NHS Trust</p> <p>HBDCA was approached in early March, 2023, by the Hammersmith Haemophilia Centre to explore, in the coming months, the engagement of HBDCA to provide psychological support to its patients and what form that might take dependent on budget etc. Although still delayed, it is anticipated, funding allowing, that this partnership will commence in 2026.</p> <p>The London Clinic</p> <p>HBDCA has recently commenced supporting its first client at the London Clinic.</p> <p>Queen Elizabeth Hospital Birmingham Haemophilia Department</p> <p>HBDCA has been supporting patients at Birmingham on an informal basis since March, 2023. And despite Birmingham Haemophilia Centre being funded by NHS England to have an IBPS psychologist, it was mutually agreed by the Haemophilia Centre and HBDCA that any patients currently being supported by HBDCA would continue this support, working in tandem with the IBPS psychologist who would be assigned any new patients.</p> <p>HBDCA facilitated an Infected Blood event on 8 August. 2024, for Infected and Affected members of the community. Christina Burgess was joined by Ros Cooper, HBDCA Ambassador, who made an invaluable contribution to the event.</p>
--	---

	<p>Addenbrookes Haemophilia Centre – Cambridge</p> <p>HBDCa was invited to meet with the Centre Director and members of the MDT in April, 2024, with a view to the Centre exploring how it might secure funding to enable HBDCa to support its patients. This situation is ongoing with the hope that funding, especially for Infected Blood support, may be forthcoming in the near future.</p> <p>HBDCa Ultra-Rare Peer Support Group</p> <p>This monthly (virtual) peer support group which commenced in the summer of 2022, is facilitated by HBDCa on a voluntary basis. It is not aligned to any Centre and is available to any women in the UK with an ultra-rare bleeding disorder.</p> <p>It now has 11 members ranging in ages from early twenties to mid-seventies. The rare disorders range from Glanzmann's Thrombasthenia, Factor VII Deficiency and Bernard Soulier Disease. The women who attend this group had previously experienced a great sense of isolation as well as issues around delayed diagnosis and treatment. For some women this group has enabled them to meet others with the same rare disorder for the very first time. This group has quickly bonded and have named themselves: Blood Sisters. The intention, funding permitting, is to bring this group together in person in the near future.</p> <p>There is a commitment from the Royal London Haemophilia Centre that an Ultra-rare wellbeing event will take place in early 2026 which would be</p>
--	---

	<p>open to women from across the UK, not just RLH patients.</p> <p>HBDCA has been able to signpost this group to other Ultra-rare initiatives and also to keep them informed of any European Rare and Inhibitor Network (ERIN) activities they might like to participate in. HBDCA has encouraged the members of this group to create their own WhatsApp group so that they can keep in touch with each other in-between meetings, as an added layer of support for each other.</p> <p>Quote from a member of the Rare Peer Support Group:</p> <p><i>‘HBDCA and our peer support group has been such a welcome eye opener for me. It has enabled me the opportunity to meet other women and other mothers of children with ultra-rare bleeding disorders, providing me with a sense of community for the very first time, and a reassurance that I am not alone, which I had not experienced until now’.</i></p> <p>The Terrence Higgins Trust/Macfarlane Trust Counselling Service (THT)</p> <p>Having commenced support to the Infected Blood community in July, 2020, HBDCA remains the only named psychological support charity on the THT list of approved therapists and psychological support organisations. As stated previously, it is very important to note that THT clients are able to choose whichever therapist or organisation they might like to support them from this list or indeed can choose any therapist they prefer separate to this list.</p>
--	---

	<p>The client list for this vulnerable cohort continued to grow during 2024 – 2025 with HBDCA now supporting 13 people. Approximately 250 one-to-one psychotherapeutic sessions were provided to THT clients during this year.</p> <p>Separately, having mutually agreed and identified that there was a need for this, THT contracted HBDCA for a two-year period, which commenced at the end of January, 2023, to facilitate 4 peer support groups per month for the Infected Blood community. 36 peer support group meetings were held during this year. The contract concluded at the end of January, 2025.</p> <p>Continuation of Infected Blood Peer Support</p> <p>HBDCA has continued, on a voluntary basis, to facilitate (virtually) Infected Blood Peer Support meetings. The meetings last on average 90 minutes each with 2 meetings now being held per month. Attendees have found these meetings essential and have alleviated their sense of isolation and continued despair during difficult times.</p> <p>As an addition to these meetings, HBDCA held an informal Infected Blood meeting in Bournemouth, on 29 June, 2024, in order to connect, in-person, members of the Infected Blood community from that region.</p> <p>England Infected Blood Support Scheme (EIBSS)</p> <p>From April 2024 to March 2025 HBDCA carried out more than 100 psychotherapeutic therapy sessions for 10 clients, as well as completing pre-assessment sessions for each one.</p>
--	--

In addition to providing this psychotherapeutic therapy, HBDCA was also required to write letters on behalf of each client to EIBSS in support of their therapy to justify why it was needed in order for the clients to be awarded funding by EIBSS. For some clients during this period more than one letter was required.

The majority of HBDCA's EIBSS clients apply for further funding beyond that provided for one year's psychotherapeutic support. Some of our clients are now in their fourth year with HBDCA. This is testament to the level of trust between these very vulnerable, complex clients and our expert psychotherapists.

Listening Ear

It is important, for the recording of HBDCA's work and output during this particular period, to note, as in previous years, that each client, whether from the Haemophilia Centres, from THT or from EIBSS, are each called and spoken with at length on at least one occasion, frequently two or three times, by the Director, as part of the HBDCA process.

These calls are used to introduce HBDCA to the client and its work, to explain to them the psychotherapeutic journey in order to put them at ease if they are nervous. And for HBDCA to learn a little about the client and their issues to ensure that HBDCA does not lose sight of the community it serves.

Clients and patients also know that they can contact HBDCA at any time

	<p>should they need to have a call with someone.</p> <p>Several hundred calls have been carried out to patients/clients by the Director in 2024 - 2025. This has provided an additional layer of support to the Infected Blood community during this difficult year.</p> <p>Quote from a member of the Infected Blood community:</p> <p><i>'In my personal view, HBDCA is such an important organisation that gives the utmost psychological and mental health help to so many tragic victims of the contaminated blood scandal. It is the only group that actually understands the mental and psychological harm that has been inflicted on the victims and their families.'</i></p> <p>Alan Burgess – Co-chair Birchgrove Group World Federation of Hemophilia Congress 2024 – Madrid</p> <p>Christina Burgess attended the WFH Congress in Madrid, 21 – 23 April, 2024. Whilst there she was able to meet with European colleagues. She attended useful sessions on the new technological advances in bleeding disorder care which she was then able to share with the HBDCA team. She also participated in meetings on the topic of psychological wellbeing and psychosocial initiatives, promoting HBDCA and its work. She met with members of the Kyrgyz community which HBDCA supports on a voluntary basis as well as with representatives from the World Federation of Hemophilia who were very interested to learn of HBDCA's work.</p> <p>Infected Blood</p>
--	--

It cannot be underestimated just how impactful the Infected Blood situation has been for this vulnerable community during this year, and also for HBDCA itself, with the need to ensure that expert, empathetic, timely support was available whenever needed.

Quote from Lisa Fowler, HBDCA Senior Associate, Psychotherapist:

'Reflecting on the previous year what feels most present is the continuing impact of the ongoing compensation process on the infected blood community. This impact has been profoundly felt in those both directly and indirectly impacted. As therapists coming alongside clients through this period I feel we hold an awareness of the magnitude of all that this is whilst feeling, very powerfully at times, the depth of pain and sorrow that remains for this community.

As ever, working with the IB community continues to be one of the greatest privileges of my life. To be trusted by this community that has previously been unable to trust with any sense of safety will remain with me as a deep honour for many years to come.'

**Infected Blood Public Inquiry
Final Report - 20 May 2024**

HBDCA made a strategic decision to have a physical presence in Westminster from 19 May to 21 May, in order to provide support to the Infected Blood community during such a momentous time. Especially for the publishing of the Final Report on 20 May, and the lead up to that day, which had been waited for, for many decades, by so many.

HBDCA's assessment that psychotherapeutic and psychosocial

	<p>support would be needed was completely justified.</p> <p>More than 100 people were provided with support and a listening ear by HBDCA and its team during this time. It is impossible to put into words just how impactful those days were.</p> <p>Quote from two individuals who required support during the Public Inquiry Final Report days:</p> <p><i>'How wonderful it was to spend time with you and your lovely colleagues. Your enthusiasm and genuine warmth and kindness was a real boost for anyone. You have a way of putting people at such extreme ease. Your work as a counsellor could never be undervalued. Helping the Haemophilia family and beyond, with your love and compassion. You are so sincere and we would highly recommend if anyone needed to talk without prejudice or judgment, you would be that go to person.'</i></p> <p>On the one hand was the emotion and the elation of 20 May with its wide-reaching and detailed Final Report, a chance for justice and truth to be finally revealed, but on the other hand, the devastating realisation on 21 May, that the response to the Final Report and its recommendations from the government, and how the proposed compensation process was to be decided and managed, was so complex that the process would take years to conclude. This was devastating to a community who had been waiting for thirty years and more for justice, with the realisation that some people might not live to see justice served or a true acknowledgement offered to them for their deeply-felt loss and trauma.</p>
--	---

	<p>Quote from a key campaigner in the Infected Blood community:</p> <p><i>'As someone who speaks to victims of the Infected Blood scandal daily, and as an infected person myself, I have witnessed the incredible value of HBDCA's Infected Blood Wellbeing Days in many ways. The weight of isolation felt by so many in the community is instantly lifted by meeting others, both infected and affected, in an environment perfectly curated by Christina to enable people to experience a safe space for perhaps the first time. These events are, for so many, the beginning of their healing pathway, and, as such, their worth cannot be overstated.'</i> Andrew Evans – Chair, Tainted Blood</p> <p>NHS England Stakeholder Group</p> <p>HBDCA has been involved, since its inception, with the NHS England Stakeholder group, with Christina Burgess, along with other members of the HBDCA team sharing knowledge, insight and expertise with the new psychologists coming into the IBPS.</p> <p>On 18 December, 2024, Christina Burgess was a facilitator at the inaugural NHS England IBPS Induction Day in London. HBDCA was instrumental in persuading NHS England that in-person inductions for any new IBPS psychologists should be mandatory. The event proved to be extremely insightful for attendees, with some of the new psychologists reaching out further to HBDCA, beyond that day, in order to gain additional, valuable insight into this unique community. HBDCA will continue to provide expertise in this area for as long as needed. The Induction Day was also attended and participated in by HBDCA Ambassador, Ros Cooper,</p>
--	---

	<p>who was able to share invaluable patient expert experience with the new psychologists.</p> <p>Quote from David Foley, CEO, IBCA:</p> <p><i>'May I thank HBDCA for the many years of supporting this community with your invaluable work in the face of the immense psychological harm that was caused by the infected blood scandal.'</i></p> <p>Haemophilia Centres Peer Review Participation</p> <p>From early 2024 onwards HBDCA provided input and information for four Haemophilia Centre Peer Reviews, giving insight into the psychological/psychosocial support being provided by those Centres:</p> <p>Oxford Royal London Kent and Canterbury St George's, Tooting</p> <p>All of the information provided by HBDCA was positively reviewed.</p> <p>HBDCA Team-building Week-end September, 14 – 15 2024</p> <p>A highly useful session on new treatments was presented to the HBDCA team and trustees by Dr Kate Khair, along with the opportunity for the psychotherapeutic team to have an in-person supervision session. There was also a virtual meeting organised with HBDCA interpreter, Aizat Aidarbekova, from Kyrgyzstan, to outline the importance of the work carried out there by HBDCA. HBDCA Trustees held an in-person Trustees' Meeting plus a strategy meeting with the whole HBDCA team in order to</p>
--	---

	<p>explore and discuss future plans for HBDCA.</p> <p>HBDCA Psychology in Gene Therapy Project</p> <p>Following the success in 2023 of the UK-wide Gene Therapy Roundtable facilitated by HBDCA to commence the creation of Principles of Psychology in Novel Therapies (Gene Therapy), this project was adopted by EAHAD (European Association for Haemophilia and Allied Disorders). A further, Europe-wide roundtable with 55 attendees was held in February, 2024. with the outcome being that the EAHAD European Principles of Psychology in Novel Therapies (Gene therapy) are now being developed.</p> <p>Two academic papers on this subject, co-authored by Christina Burgess along with her colleagues on the EAHAD Psychosocial Committee, were published in <i>Haemophilia</i> during this period, and the expectation is that the EAHAD European Principles of Psychology in Novel Therapies will be launched at the EAHAD Congress in Brussels, in February, 2027.</p> <p>European Association of Haemophilia and Allied Disorders (EAHAD)</p> <p>Christina Burgess was elected Chair of the EAHAD Psychosocial Committee at the EAHAD Congress in February, 2024. The initial term is for three years, with the possibility of a further three-year term.</p> <p>HBDCA is extremely proud to have been the instigator of this important project with the hope that these Europe-wide Principles will bring enormous benefit from a</p>
--	---

	<p>psychological/psychosocial perspective to all patients undergoing gene therapy, enabling each one of them to have equitable access to high quality psychological provision, across Europe.</p> <p>In February, 2025, Christina Burgess was invited to participate in two new EAHAD working groups: Joint Health (the impact from a psychological and psychosocial perspective) and Women with Ultra-rare coagulation factors.</p> <p>European Haemophilia Consortium (EHC)</p> <p>Christina Burgess continued in her role as a long-standing member of the EHC Inhibitor Working Group (IWG) which has now transitioned to becoming the ERIN (European Rare and Inhibitor Network) Committee, facilitating peer support groups for the partners of people with an inhibitor and helping to facilitate the annual ERIN Summit. She stood down from her formal role in ERIN in February, 2025, but will continue to be involved informally.</p> <p>HBDCA website</p> <p>Although delayed, HBDCA is now currently undergoing a major overhaul of its website to bring it completely up-to-date. Further content to its website will reflect the different and diverse cohorts it works with and areas of work it carries out, such as Women with Bleeding Disorders, Newly Diagnosed, Ultra-Rare Bleeding disorders, Novel Therapies (Gene Therapy), and work on behalf of the LGBTQ+ community. It will also highlight HBDCA's voluntary work and recognise further the team and the value they bring to HBDCA.</p>
--	--

	<p>HBDCa also intends, in the near future, to create a special legacy section on its website for the Infected Blood community so that the immense impact on this community is never forgotten and in order to demonstrate how important psychological support has been for this community, how greatly needed, and how, despite being a small charity, HBDCa has been at the forefront of this provision.</p> <p>The HBDCa website, which is an extension of the team and the work being carried out, as well as a source for signposting to external organisations and partners, is a useful resource for the community.</p> <p>HBDCa Governance and Team Support</p> <p>HBDCa continues to provide its psychotherapeutic team with monthly supervision sessions.</p> <p>This is especially important due to the work they carry out supporting people enduring deep trauma in the Infected Blood community. To that end, HBDCa also now funds additional supervision sessions which specifically focus on Infected Blood support being carried out. HBDCa has recognised that working in psychotherapeutic provision can be very impactful to the psychotherapists themselves. Providing supervision is good practice and helps to ensure that the team feels valued and supported in the essential work they carry out.</p> <p>HBDCa also continues to hold a monthly Leadership meeting between the Director and the Senior Associate psychotherapeutic team, with a remit to continually improve, update, and add</p>
--	---

	to, HBDCA's governance documents and policies. These meetings are ongoing.
	<p>HBDCA Volunteer Project</p> <p>HBDCA continues with its volunteer project with the Haemophilia and Bleeding Disorders community in Kyrgyzstan which began with a workshop in March, 2022. Up until this project there had been no psychological support available at all to this vulnerable community.</p> <p>Since then, HBDCA has been facilitating monthly peer support groups for three different groups: Single Mums, Parents of Newly Diagnosed Children and Young Adult Men with Haemophilia, all on a voluntary basis. Three members of the HBDCA team have also volunteered some hours per month each to support three very vulnerable people within the Kyrgyz community with (virtual) one-to-one psychotherapy.</p> <p>HBDCA, including key involvement from its Trustee, Dr Kate Khair, is in the process of applying to EAHAD for a research grant to visit Kyrgyzstan and make a short film about the community there and the psychological and psychosocial impacts for people with bleeding disorders in less-resourced countries. The aim of the film would be to share this insight with other bleeding disorder organisations such as the EHC and World Federation of Hemophilia in the hope that they might use this project as a template for the creation of beneficial projects in other less-resourced countries.</p> <p>.</p>
Statement confirming whether the trustees have had regard to the	The trustees of HBDCA adhere at all times to the principles and guidance issued by the Charity Commission on

guidance issued by the Charity Commission on public benefit	public benefit and apply these to all activities carried out by HBDCA.
---	--

Achievements and Performance

Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.	<p>The Royal London Hospital Haemophilia Department</p> <p>HBDCA's provision of psychotherapeutic support at the Royal London has seen the patient numbers grow and the relationship with the multidisciplinary team continue to develop very positively. This work has benefitted from the addition of HBDCA's part-time child psychologist.</p> <p>Christina Burgess continues to have an NHS Smart Card, along with remote access to the RLH system.</p> <p>The two peer support groups: Adults with a Bleeding Disorder, and Women with Bleeding Disorders which commenced in March, 2022 continue to be facilitated on a monthly basis. As with the ultra-rare peer support group, HBDCA's intention is to bring these two cohorts together at least once a year at in-person meetings next year. Attendees in both groups have developed a camaraderie with each other and have all found a welcoming space to be with other people experiencing similar lives and issues.</p> <p>The Terrence Higgins Trust/Macfarlane Trust Counselling Service (THT)</p> <p>This year, as previously, there have been individuals and their family members who have availed themselves of psychotherapeutic support, in some cases for the first</p>
---	---

time in 30 years. This provision of high-quality, effective psychotherapeutic support is being made available through the HBDCA team, with its deep insight into bleeding disorders and into the Infected Blood community. HBDCA believes that this unique insight, which it prides itself on being its USP, is essential in providing much-needed, long-awaited, effective psychotherapeutic support to this vulnerable group. With the compensation process and its complexities, which are being managed by IBCA (Infected Blood Compensation Authority), going to take a long time to see the offer of compensation made to all who deserve it, the coming few years, during this stressful and uncertain time, will see this support needed more than ever.

England Infected Blood Support Scheme (EIBSS)

During the period 2024 - 2025 HBDCA has enabled further clients to access insightful, high-quality support not previously available to them. The EIBSS provision is particularly important for the Hepatitis C cohort who are not eligible for provision of counselling through the Terrence Higgins Trust/MacFarlane Trust route. Despite some uncertainty as to whether EIBSS would continue funding HBDCA in this work, at present this concern has been unfounded.

Education and Information

Through continuing, effective communication and by developing relationships with like-minded

	<p>healthcare colleagues and organisations such as Haemnet, the HPA, Haemosexual, The UK Haemophilia Society, the Hepatitis C Trust, the Terrence Higgins Trust, Local Families with Bleeding Disorders, and the Kyrgyz National Member Organisation (NMO), along with listening to individuals within the community, HBDCA has been able to reach out to, and inform, not only those in the Infected Blood community but also the wider bleeding disorder community, including women with bleeding disorders and with ultra-rare disorders, those undergoing gene therapy trials and also healthcare professional colleagues across the MDT, about the psychological/psychosocial issues people with bleeding disorders and their family members experience.</p> <p>HBDCA has also offered resilience sessions to Haemophilia Centre MDTs. It believes that these will be especially helpful for Haemophilia Centres which might have been criticised in the Public Inquiry Final Report, or where previous members of staff at those Centres might have been individually criticised, for their involvement in the Infected Blood tragedy.</p>
	<p>Team Meetings post Covid-19</p> <p>HBDCA continues to hold a weekly Zoom meeting with its psychotherapy team, and regular Zoom meetings with the Trustees. This is an ongoing and important part of HBDCA culture, which started at the beginning of the Covid-19 pandemic, with the belief that supporting one's team and colleagues and maintaining excellent channels of communication will</p>

	ensure improved support for clients and patients.
--	---

HBDCA Strategic Plan 2024 - 2025

HBDCA will continue to provide effective, high-quality, tailored psychosocial support to patients, their family members and carers at The Royal London Hospital Haemophilia Centre

HBDCA will provide psychosocial support to a second London Centre (Hammersmith and St George's, Tooting) and their patients, family members and carers

HBDCA will provide psychosocial support to the bleeding disorder community at other hubs across the United Kingdom, namely: The Kent and Canterbury Haemophilia Department, University Hospital Southampton Haemophilia Department, and Oxford University Hospital Haemophilia Department

HBDCA will also provide ad hoc support to Haemophilia Centres across the United Kingdom where required (Birmingham, Addenbrookes, Nottingham and Leeds)

HBDCA will continue to support members of the Infected Blood community across the United Kingdom through the provision of specialist psychotherapy and by facilitating bi-monthly peer support groups. This will be especially important from May 2024 onwards following the publishing of the Infected Blood Final Report and the impact this will have on the Infected Blood community

HBDCA will continue to use its insight and expertise to inform the Infected Blood Psychological Service (IBPS)

HBDCA will continue to run a monthly peer support group on a voluntary basis for women across the UK with ultra-rare bleeding disorders

HBDCA will advocate for psychosocial support to be made available for all people undergoing novel therapies including the creation in the near future of a peer support group

Achievements against objectives set in Strategic Plan 2024 - 2025	<p>HBDCA has now fully returned to supporting the Royal London Hospital Haemophilia Department.</p> <p>Although not formally yet present at another London Haemophilia Centre, it has continues to carry out work for St George's Haemophilia Department, in Tooting, south London, with an expectation also of supporting patients</p>
---	---

	<p>at the Hammersmith Haemophilia Centre in the near future.</p> <p>HBDCA continued during this period to provide support for patients at the Kent and Canterbury Hospital Haemophilia Department.</p> <p>With Oxford, Birmingham and Southampton Haemophilia Centres now engaging HBDCA to support its patients and family members, HBDCA will have fulfilled that element of its 2024 – 2025 Strategic Plan.</p> <p>HBDCA continues to support the Infected Blood community across the United Kingdom very effectively through its work with Haemophilia Centres, with the Terrence Higgins Trust/MacFarlane Trust counselling service and through the England Infected Blood Support Scheme (EIBSS). HBDCA has continued to demonstrate committed, expert support for this community including in providing expertise and insight to the IBPS and providing invaluable insight to the continued work of the Infected Blood Public Inquiry team on psychological issues and themes in order to positively inform decisions affecting this vulnerable community post the Final Report.</p> <p>HBDCA continues to actively engage with like-minded charities such as the UK Haemophilia Society and the Hepatitis C Trust in advocating for the Infected Blood community.</p> <p>HBDCA has continued to keep up to date with all ongoing outcomes of the Public Inquiry, especially since its conclusion, and the difficult times being experienced by both the Infected and Affected cohorts since then. Due to</p>
--	--

	these ongoing issues, HBDCA has contributed to an upcoming smaller Inquiry which will take place in May, 2025, by providing a written statement to the Inquiry team in December, 2024, centred around the ongoing psychological distress still being experienced by the IB community, with this statement being requested by the Public Inquiry to be used as evidence.
Investment performance against objectives	All the objectives achieved during the period 1 April 2024 – 31 March 2025, were carried out within the monies received by HBDCA.

Financial Review

Review of the charity's financial position at the end of the period	<p>HBDCA commenced the period with £35,988 in it's account.</p> <p>Throughout the year HBDCA fulfilled many activities. The details of the financial position and activity is contained within the Financial Return for HBDCA for April 1, 2024 – 31 March, 2025.</p>
Statement explaining the policy for holding reserves stating why they are held	<p>It is HBDCA's policy to hold reserves in order to safeguard the long-term future and sustainability of the CIO. And with the security reserves offer, for HBDCA to have the ability to maintain, continue to provide and also to increase this provision, the specialised psychological and psychosocial support it offers the bleeding disorder community.</p>
Amount of reserves held as at 31 st March 2025	£46,290.42
Other financial notes	<p>HBDCA as received £1,050 in donations during the financial year</p> <p>HBDCA is now registered for VAT.</p>

Additional information

A description of the principal risks facing the charity	<p>The principal risk for HBDCA would be lack of, or loss of, funding for the provision of psychological care. Through keeping costs and overheads to a minimum, by only working with psychotherapists of the highest calibre and by HBDCA's reputation continuing to grow within the bleeding disorder arena, and the benefit of the psychological care it provides being recognised more widely, HBDCA hopes to avoid this risk.</p> <p>A further risk would be for HBDCA not to have enough members of the team to fulfil the therapeutic requirements it is</p>
---	---

	<p>committed to provide. HBDCA now has nine psychotherapists in its team as well as a part-time child psychologist.</p>
In conclusion	<p>HBDCA has continued to grow and to thrive.</p> <p>As well as client/patient numbers increasing this year, in all areas of HBDCA activity, including at new centres it has provided psychotherapeutic support to, HBDCA has also increased its team and put in place new strands of support for the team, including the team-building week-end, and continuing to ensure that HBDCA governance documents and policies are fit for purpose.</p> <p>HBDCA benefits from a committed, supportive and engaged group of Trustees with the number of trustees also expanded who ensure HBDCA achieves its aims and objectives, and aspires always to enact its vision, whilst ensuring these are always carried out within HBDCA's means in order to ensure its future is protected and the services it provides have longevity.</p> <p>HBDCA has engaged an accountant, EBJ Accounting, during this year which has been very beneficial in ensuring HBDCA remains in good financial shape.</p> <p>HBDCA has continued to offer a safe, welcoming environment to all those it has supported during the period of this report, providing a high level of expertise from an experienced, passionate and empathetic team.</p> <p>During this period HBDCA carried out a small diversity study and is reassured from its conclusion that HBDCA is a welcoming, inclusive and diverse organisation.</p>

	<p>HBDCa also continues to provide sound support for the psychotherapeutic team and to continue to provide the team with more opportunities for learning and supervision.</p>
--	---

Declarations

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)		
Position (eg Secretary, Chair, etc)		
Date		

HBDCA DIRECTOR'S REPORT 2024 – 2025

This period has been an unprecedentedly busy and productive one for HBDCA and for myself, as Director. This Report is an addendum to the main Trustees' Report with the purpose of highlighting some of the work I carry out as HBDCA Director which greatly informs or contributes to the work HBDCA carries out as a whole.

Haemophilia Centres

HBDCA continues to support patients at the Haemophilia Centre, Oxford. I have also facilitated two Infected Blood events there and attended meetings with the Centre Director and MDT. I also visited, in person, two particularly vulnerable patients during this period.

HBDCA concluded its negotiations with University Hospital Southampton Haemophilia Centre during this period and commenced supporting patients there in February, 2025. I facilitated an Infected Blood event which was well-received. It was attended, as an observer, by the IBPS psychology assistant to help them gain further insight into the IB community.

HBDCA continues to support patients at Birmingham, as well as, for the long-term, patients and family members at the Royal London Haemophilia Centre. HBDCA continues to support patients and family members, until the end of 2025, for the Kent and Canterbury Haemophilia Centre. I have facilitated a number of Infected Blood events during this time, accompanied on occasion, very ably by our Trustee, Joseph Peaty and our Ambassador, Ros Cooper.

I act as the main contact for all the Haemophilia Centres we work with and as liaison with Centre Directors and MDTs. I am also the governance lead and work closely with the HR departments to ensure that honorary contracts, for instance, are up to date, and any statutory and mandatory training completed by the psychotherapeutic team.

HBDCa has also recently commenced providing psychological support to patients at the London Clinic, the first private Haemophilia Clinic in the UK.

HBDCa Psychotherapy Team

HBDCa's team of expert psychotherapists has grown from the original team of four psychotherapists in 2018 when HBDCa was founded, each of whom is still thankfully with HBDCa, to a team of nine psychotherapists as well as now a wonderful child psychologist, and a music therapist. As the whole team is aware, especially the HBDCa Trustees and Ambassador, HBDCa has always grown in an organic way to ensure that team members share the same principles, ethos and passion for supporting this community. Through maintaining this recruitment principle, despite growing in numbers, HBDCa has now created an expert team who are able to live up to HBDCa's USP (unique selling point) of having deep insight and expertise in supporting the bleeding disorder community along with great empathy and compassion for those we work with.

HBDCa clientele

Our client base continues to grow. We currently support approximately 200 people on an ongoing, long-term basis, along with a small number who might reach out at times of crisis, for short-term support. This short-term work might come from Haemophilia Centres HBDCa does not have formal contracts with who reach out to HBDCa for those patients they recognise would benefit from our expertise. This applies currently to four Haemophilia Centres who reach out to HBDCa on an ad hoc basis.

In addition, this year, HBDCa will have supported at least a further 200 people, whether patients, clients, or family members, who might participate in wellbeing events, or in peer support groups or meetings we have participated in. Many of these individuals come from the Infected Blood community and are an indication of how much this support is needed.

As HBDCa Director, during this year, I have spoken with countless people, hundreds in number, especially from the Infected Blood community, many of these calls being in a 'listening ear' capacity. Having spoken with them, if required, I am then able to refer them to one of the psychotherapeutic team, or to signpost them to organisations or individuals who might help them.

On HBDCa's behalf, I have continued to write numerous letters in support of EIBSS (England Infected Blood Support Scheme) applications from the IB cohort for

funding for this support. Again, more than one letter might be required before funding is granted or renewed for a further year.

HBDCA Trustees and Ambassador

HBDCA has six Trustees, under the excellent chairmanship of Nina Beer. They are:

Nina Beer
Cynthia Creavalle
Joseph Peaty
Maryam Samina
Dr. Kate Khair
Farid Gasanov

HBDCA also has an excellent Ambassador, Ros Cooper, who continues to show great commitment to the work HBDCA carries out. All our Trustees' input, expertise and insight is invaluable and especially appreciated during such an impactful year.

Support for the psychotherapeutic team

It has been essential to ensure, given that the HBDCA psychotherapists are spread across the UK and beyond, that we provide pastoral support to the team, enable sharing of knowledge and continued insight into the bleeding disorder community, especially when it comes to new therapies and treatments. For instance, gene therapy. And, also, crucially, to create a sense of belonging for our colleagues within the HBDCA team.

To ensure the above is possible the HBDCA team meets (virtually) almost every Monday throughout the year, facilitated by myself. The psychotherapeutic team also meets every month for peer supervision. HBDCA has also put in place separate supervision for our child psychologist, Dr. Hannah Dunford. Importantly, the number of peer supervision sessions has been increased to include specific Infected Blood supervision in order to ensure the team is able to fully process the extremely difficult and complex work it carries out on the coalface of support for this vulnerable community.

The Impact of Infected Blood on the community and on HBDCA's work

With the publishing of the Final Report from the Infected Blood Public Inquiry on May 20, 2024, HBDCA has continued to witness, post the publication, a major increase in anxiety, re-triggering of trauma, and fear of the future, from this community. The community remains exhausted and nervous, indeed, negative

stressors for many have actually increased, due to the government's response to the Inquiry recommendations and also the complexities and delays with the compensation offered, with the process now being overseen by IBCA (Infected Blood Compensation Authority), which was not set up until post the Inquiry Final Report.

Individuals and families are having to continue to wait, especially those in the Affected cohort. Additionally, with people passing away on a weekly basis, these individuals and their family members may never receive the justice they deserve, the apology and acknowledgement they have waited for, for so long, or the financial compensation which should have been provided to them, many years before.

Due to the collective trauma and angst witnessed by the team, as Director, I continue to guide them and continue to offer enhanced support to them, post the publishing of the Final Report, due to the fact that, as had previously been predicted last year, this period of uncertainty and anxiety for the Infected Blood community will continue for quite some time to come. I must also point out that despite the new NHS England IBPS (Infected Blood Psychology Service) now being mostly in place, HBDCA's insight and expertise cannot be underestimated and may be needed more than ever.

As mentioned in the Trustees' Report, HBDCA made the strategic decision to have a physical presence at the Final Report in order to provide much-needed support throughout the key days surrounding the launch date. HBDCA could not have done this without members of its exceptional psychotherapeutic team being on hand throughout. I am extremely proud that HBDCA was there to provide an essential service during this time and that we stepped up to the mark.

During this year, quite understandably, HBDCA saw an increase in clients and patients being referred to us or self-referring themselves to us, requiring psychotherapeutic support related to their trauma as members of the Infected Blood community, whether 'infected' or 'affected'. HBDCA has continued to provide two peer support group meetings per month for the IB community, on a voluntary basis, which I facilitate. Although the numbers attending have been relatively small, fluctuating from four to eighteen, the feedback from attendees, and their commitment to attend the meetings twice monthly, has continued to demonstrate how invaluable these sessions have been during such a difficult and challenging time.

HBDCA also held a team-building week-end in September, 2024, as an added layer of support for the HBDCA team, allowing them to process, with each other, as part

of the week-end, an in-person supervision session, to decompress from the intensity of the work they carry out. The team-building day was needed more than ever this year.

HBDCA Membership of NHS England Stakeholder Group re Infected Blood

Since July, 2023, I have represented HBDCA having been invited to be a member of this group, to try to ensure that the new Infected Blood Psychology Service (IBPS) which is being managed by NHS England, will be fit for purpose and provide the highest level of psychological support possible. As a matter of course, HBDCA will continue to collaborate, as it has always done, with these new colleagues, to share with them our unique and in-depth knowledge of the Infected Blood community. This work will continue for a few more years at least.

HBDCA's work with the wider bleeding disorder community

Although the support required for the Infected Blood cohort greatly increased during this time, HBDCA continued, throughout the year, to provide expert psychotherapy to many other groups within bleeding disorders: women, young people, ultra-rare disorders, ageing, those who experience long-term, chronic pain and those with needle-phobia, both adults and children, as examples.

The Director's Voluntary Work

Rare Peer Support Group

On a voluntary basis, supported by the Trustees at HBDCA, I facilitate a monthly peer support group (virtual) for women with ultra-rare bleeding disorders which is in its fourth year now. There are 11 members of this group from across the UK. The group was set up to try to reduce the sense of great isolation so many of these women feel. They have created a WhatsApp group so they can speak with each other and support each other in between the peer support meetings. This has proved invaluable to many of them as they have found a sense of community with each other they had not had before.

EAHAD (European Association for Haemophilia and Allied Disorders)

I work with a European organisation: EAHAD. Having been a member of the EAHAD Psychosocial Committee since 2018, in early February, 2024, I was honoured to be elected Chair. I was also at that time invited to be a member of two new EAHAD working groups: Joint Health, and Women with ultra-rare coagulation disorders. My hope is to share my psychosocial expertise with these two groups,

whilst at the same time, being able to share valuable learnings from my EAHAD work with the HBDCA team.

EHC (European Haemophilia Consortium)

Running the Ultra-rare peer support group (now in its third year) has enhanced the work I did whilst a member of the EHC ERIN (European Rare and Inhibitor Network) Committee, which I recently stepped down from. The ultra-rare community across the UK and Europe has been greatly underserved and is only now being provided with more timely and more accurate diagnoses.

The work I am currently involved in with EAHAD will contribute further to the ultra-rare cause. I also intend to continue to support EHC ERIN initiatives going forward, on a less formal basis.

Kyrgyzstan

I continue to facilitate, more than three years' on, on a voluntary basis, with HBDCA's blessing, four monthly peer support groups for Kyrgyzstan due to no psychological or psychosocial support being available for the bleeding disorder community there.

I am only able to carry out this work with the invaluable help of our interpreter, Aizat Aidarbekova, as most of the attendees do not speak English. The initiative has proved invaluable to this community. Three members of the HBDCA team also donate some hours per month at no charge to support the most vulnerable people in these groups so that they might have one-to-one psychotherapeutic support, for which I am extremely grateful to those team members.

Conclusion

The work carried out by myself as HBDCA Director, always has HBDCA at its core. Being a member of EAHAD and working alongside the EHC and attending and participating as a key facilitator or speaker on psychological and psychosocial topics during their congresses, conferences and roundtables, ensures that HBDCA is a visible and recognised presence on the European stage. My work, as a representative at all times of HBDCA, and HBDCA's incredible work itself, is enabling HBDCA to be recognised more and more frequently not only in the UK but more widely in Europe, and in the World Federation of Hemophilia arena, as being an essential psychological entity when it comes to the provision of expert, improved mental wellbeing support for all groups within the bleeding disorder community.

My aspiration for the coming year and for HBDCA's future, is that HBDCA continues to provide high quality, meaningful, psychotherapeutic, psychological and psychosocial support, to as many people as we are able to, within our means.

To increase HBDCA's reserves so that our foundation continues to strengthen so that we can feel confident that HBDCA will be able to provide this much-needed service long into the future.

I especially hope that HBDCA continues to grow organically as a team, working together in an environment which is supportive and kind to each one of its members. Where HBDCA can provide opportunities for growth and for learning, which we can share also with external colleagues. And that HBDCA continues to celebrate diversity and inclusivity, where all are welcome, and where all those we support find a place of safety and trust.

I am hugely proud of the fact that HBDCA is a very collaborative organisation working not only with our colleagues at Haemophilia Centres, but also colleagues at the EHC, EAHAD, the UK Haemophilia Society, the Hepatitis C Trust, the Terrence Higgins Trust, Haemnet, Haemosexual, the HPA, NHS England, Local Families with Bleeding Disorders, and the Kyrgyz Haemophilia Society, sharing our knowledge, expertise and insight for the benefit of all.

I would like to end this report by thanking everyone I have worked with this year. Thank you especially to the brilliant HBDCA Trustees, our Ambassador, and to the incredible HBDCA team: Lisa Fowler, Clare Nield, Marion MacGillivray, Anila Babla, Angela Johnson, Alicia Fowkes, Helen O'Mahony, Eve Jones, Jennifer Wainman, Dr. Hannah Dunford, Patrick Browne (music therapist), Aizat Aidarbekova (interpreter), Dr. Kerry-Ann Holder (supervision) and our great Accounts colleague, Emilia Bowzyk. You have all gone above and beyond this year.

Thank you all, for enabling HBDCA to make a positive difference to those we work with and support. Through you all, HBDCA, as a small charity, has had a great and life-affirming impact on the bleeding disorder community.

THANK YOU.

Christina Burgess

Founder and Director

HBDCA



Section A

Independent Examiner's Report

Report to the trustees	Haemophilia & Bleeding Disorders Counselling Association		
On accounts for the year ended	31 st March 2025	Charity no (if any)	1191416
Set out on pages	1		

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31/03/2025**.

Responsibilities and basis of report

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

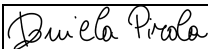
I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

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 which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did 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.

Signed:  **Date:** 18/01/2026

Name: Daniela Pirola MAAT AATQB

Relevant professional qualification(s) or body (if any): Qualified and licenced member of the Association of accounting technician

Address: 31 Vincent Close

Newmarket

CB8 7AN

Section B**Disclosure**

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

Balance Sheet

Haemophilia & Bleeding Disorders Counselling Association As at 31 March 2025

	NOTES	31 MAR 2025	31 MAR 2024
Current assets			
Debtors	3	62,736	51,367
Total current assets		62,736	51,367
Creditors: amounts falling due within one year			
Trade creditors	4	(500)	-
Other creditors	4	8,750	22,158
Other taxes and social security	4	8,196	9,854
Total creditors: amounts falling due within one year		16,446	32,012
Net current assets (liabilities)		46,290	19,356
Total assets less current liabilities		46,290	19,356
Net assets (liabilities)		46,290	19,356
Capital and reserves			
Reserves brought forward - restricted		522	11,396
Reserves brought forward - unrestricted		18,834	(601)
Profit and loss account		26,934	8,561
Total equity		46,290	19,356

Notes to the Financial Statements

Haemophilia & Bleeding Disorders Counselling Association For the year ended 31 March 2025

1. Basis of preparation

These accounts have been prepared under the historical cost convention with items recognised at cost or transaction value unless otherwise stated in the relevant note to these accounts.

The accounts have been prepared in accordance with:

- the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on October 2019 (the Charities SORP); and
- the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102);
- the Charities Act 2011.

The Trustees consider that there are no material uncertainties related to events or conditions that cast significant doubt on the charity's ability to continue as a going concern.

The accounts have been prepared under the Charities SORP for the first time. Although the format of the accounts differs from that applied in the past, no changes have been made to amounts previously reported.

No material prior year error has been identified in the reporting period.

2. Accounting policies

Income

Income is included in the Statement of Financial Activities (SoFA) when the charity becomes entitled to the resources, it is more likely than not that the trustees will receive the resources and the monetary value can be measured with sufficient reliability.

Performance related grants are recognised to the extent that the charity has provided the specified goods or services.

It is not practical to value the monetary value of donated time.

Expenditure and liabilities

Liabilities are recognised where it is more likely than not that there is a legal or constructive obligation committing the charity to pay out resources and the amount of the obligation can be measured with reasonable certainty.

Tangible fixed assets and depreciation

Tangible assets are included at cost less depreciation and impairment. Depreciation has been provided at the following rates in order to write off the assets over their estimated useful lives: -

25% straight line method

	2025	2024
3. Debtors		
Debtors: amounts falling due within one year		
Trade debtors	9,285	7,763
Other debtors		
Other debtors		
Accrued income	21,989	9,017
Less Accumulated Depreciation on Office Equipment	(310)	(177)
Office Equipment	709	709
Total Other debtors	22,388	9,549
Other current assets	31,063	34,055
Total Other debtors	53,451	43,604
Total debtors: amounts falling due within one year	62,736	51,367
Total debtors	62,736	51,367

	2025	2024
4. Creditors: amounts falling due within one year		
Trade creditors	(500)	-
Other creditors	8,750	22,158
Taxation and social security	8,196	9,854
Total creditors: amounts falling due within one year	16,446	32,012

The charity has no employees and, therefore, no employee earning more than £30,000 per annum.

Staff fees above consist of payments made to therapists.

None of the trustees have been paid any remuneration or received any other benefits from employment with this charity or a related entity.

Movements in Equity

Haemophilia & Bleeding Disorders Counselling Association
For the year ended 31 March 2025

2025

Equity

Opening balance	19,355.61
Reserves brought forward - restricted	(10,874.00)
Reserves brought forward - unrestricted	19,435.69
Retained earnings	18,373.12
Total equity	46,290.42

Profit and Loss

Haemophilia & Bleeding Disorders Counselling Association For the year ended 31 March 2025

	NOTES	2025	2024
Income and Charity Activities			
Income			
Donations and Grants		162,054	102,114
Total Income		162,054	102,114
Total turnover		162,054	102,114
Raising funds expenditure			
Wages and salaries			
Therapists' fees - 1-2-1 sessions		85,066	47,957
Management fee		24,202	29,380
Total Wages and salaries		109,268	77,337
Events - external, attended		641	-
Events - hosted		5,328	2,494
Total Raising funds expenditure		115,237	79,831
Charity activities expenditure			
Overheads			
Audit & Accountancy fees		4,230	3,915
Bank Fees		14	50
Consulting		-	350
Entertainment		400	-
Gifts to trustees		75	-
Honoraria		2,307	2,870
IT Software and Consumables		35	-
Postage, Freight & Courier		28	126
Printing & Stationery		97	75
Staff Training		-	48
Telephone & Internet		2,069	1,793
Travel - International		720	217
Travel - National		7,515	2,727
Well-being events		1,530	-
Total Overheads		19,019	12,170
Other expenses			
Insurance		395	385
General Expenses		336	990
Depreciation		133	177
Total Other expenses		864	1,552
Total other charges		19,883	13,722
Profit (loss) before taxation		26,934	8,561
Profit (loss) after taxation		26,934	8,561