

HBDCA

England & Wales · Charity number 1191416

Details

Status Registered

Legal form CIO

Registered 2020-09-22

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

Contact

Address 5
St Andrews House
St Andrews Park
Soham
Ely
Cambridg

Phone 07703747030

Email christina@hbdca.org.uk

Website www.hbdca.org.uk

Activities

Objects: TO PROMOTE AND PROTECT THE PHYSICAL AND MENTAL HEALTH OF PEOPLE IN THE UK AFFECTED BY A BLEEDING DISORDER, THEIR FAMILIES AND CARERS THROUGH;A)THE PROVISION OF COUNSELLING AND THERAPY;B)PROVIDING WORKSHOPS, SUPPORT AND SIGNPOSTING;C)RAISING AWARENESS OF THE NEED FOR SUPPORT FOR PEOPLE AFFECTED BY A BLEEDING DISORDER;D)PROVIDING WORKSHOPS TO PROFESSIONALS TO PROVIDE INSIGHT AND IMPROVE THE SUPPORT THEY PROVIDE TO THE BLEEDING DISORDER COMMUNITY.

Activities: To promote and protect the physical and mental health of people in the UK affected by a bleeding disorder, their families and carers through:A)The provision of counselling and therapy;B) Providing workshops, support and signposting.C) Raising awareness of the need for support for people affected by a bleeding disorder.D) Providing workshops to professionals to provide insight and i

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Other Charitable Activities
- **What:** Education/training, Other Charitable Purposes
- **Who:** Other Defined Groups

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£162,054	£135,120	-	-
2024-03-31	£102,114	£93,552	-	-
2023-03-31	£93,115	£97,743	-	-
2022-03-31	£56,737	£43,212	-	-
2021-03-31	£25,044	£23,146	-	-

Trustees

Name	Role	Appointed
Nina Janine Beer	Chair	2020-09-30
CYNTHIA CREAVALLE		2021-12-01
Joseph Paul Peaty		2020-09-30

HBDCA

England & Wales - Charity number 1191416

Accounts

Annual Report & Financial Statements

Haemophilia & Bleeding Disorders Counselling Association
As at 31 March 2025

Prepared by A-Counting Genie Ltd

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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>
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	England Infected Blood Support Scheme (EIBSS).
Relationship with any related parties	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.
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.
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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			
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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

HBDCAL Trustees' Annual Report

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

Charity name: HBDCAL
(Haemophilia and Bleeding Disorders Counselling Association)

Charity registration number: 1191416

Objectives and Activities

<p>Summary of the purposes of the charity as set out in its governing document</p>	<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>
<p>HBDCAL Strategic Overview</p>	<p>During 2024 – 2025 there were many challenges for HBDCAL.</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. HBDCAL needed to ensure that it stepped up to the mark with psychotherapeutic and psychosocial provision during this momentous time. Fortunately, HBDCAL 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>

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.

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.

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.

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.

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.

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>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>
<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>	<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>

members of this group from across the UK.

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.

The number of patients currently being supported equates to more than 60% of those patients originally referred to HBDCA by the RLH.

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.

Three wellbeing days were scheduled to take place:

- Newly Diagnosed Families
- Infected Blood
- Gene Therapy.

The Newly Diagnosed wellbeing day was postponed but will take place February, 2026.

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.

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.

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.

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.

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.

Continuing and new themes identified during psychotherapy sessions:

	<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.
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	<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.
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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

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.

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.

Quote from K&C patient:

'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.

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.

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.

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.

Clare is extremely approachable and empathetic. I feel comfortable enough that I have been able to release my emotions, enabling me to move forward.

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.'

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.

HBDCA ran an Infected Blood wellbeing event on 24 May, 2024. It was very well attended and well-received.

Two patients at the K&C are members of the HBDCA Ultra-Rare Peer Support Group.

HBDCA continues to support a couple with joint psychotherapy due to their unique circumstances.

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.

Support beyond One-to-One Therapy

In addition to individual psychotherapeutic support, taking into

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.

Oxford University Hospital Haemophilia Centre

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.

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.

Quote from Oxford patient:

'You and your team have rare and golden caring qualities and are like angels. Amazing!'

**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.

**Hammersmith Haemophilia
Department - Imperial College
Healthcare NHS Trust**

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.

The London Clinic

HBDCA has recently commenced supporting its first client at the London Clinic.

**Queen Elizabeth Hospital
Birmingham Haemophilia
Department**

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.

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.

Addenbrookes Haemophilia Centre – Cambridge

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.

HBDCa Ultra-Rare Peer Support Group

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.

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.

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

open to women from across the UK, not just RLH patients.

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.

Quote from a member of the Rare Peer Support Group:

'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'.

The Terrence Higgins Trust/Macfarlane Trust Counselling Service (THT)

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.

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.

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.

Continuation of Infected Blood Peer Support

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.

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.

England Infected Blood Support Scheme (EIBSS)

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.

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

should they need to have a call with someone.

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.

Quote from a member of the Infected Blood community:

'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.'

**Alan Burgess – Co-chair Birchgrove Group
World Federation of Hemophilia
Congress 2024 – Madrid**

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.

Infected Blood

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

support would be needed was completely justified.

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.

Quote from two individuals who required support during the Public Inquiry Final Report days:

'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.'

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.

Quote from a key campaigner in the Infected Blood community:

'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.' **Andrew Evans – Chair, Tainted Blood**

NHS England Stakeholder Group

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.

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,

who was able to share invaluable patient expert experience with the new psychologists.

Quote from David Foley, CEO, IBCA:

'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.'

Haemophilia Centres Peer Review Participation

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:

Oxford
Royal London
Kent and Canterbury
St George's, Tooting

All of the information provided by HBDCA was positively reviewed.

HBDCA Team-building Week-end September, 14 – 15 2024

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

explore and discuss future plans for HBDCA.

HBDCA Psychology in Gene Therapy Project

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.

Two academic papers on this subject, co-authored by Christina Burgess along with her colleagues on the EAHAD Psychosocial Committee, were published in *Haemophilia* 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.

European Association of Haemophilia and Allied Disorders (EAHAD)

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.

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

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.

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.

European Haemophilia Consortium (EHC)

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.

HBDCa website

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.

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.

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.

HBDCa Governance and Team Support

HBDCa continues to provide its psychotherapeutic team with monthly supervision sessions.

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.

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>
	<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>
<p>Statement confirming whether the trustees have had regard to the</p>	<p>The trustees of HBDCA adhere at all times to the principles and guidance issued by the Charity Commission on</p>

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

<p>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>	<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>
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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.
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HBDC A Strategic Plan 2024 - 2025

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

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

HBDC A 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

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

HBDC A 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

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

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

HBDC A 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>HBDC A 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>
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at the Hammersmith Haemophilia Centre in the near future.

HBDCa continued during this period to provide support for patients at the Kent and Canterbury Hospital Haemophilia Department.

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.

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.

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.

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.</p>
<p>Investment performance against objectives</p>	<p>All the objectives achieved during the period 1 April 2024 – 31 March 2025, were carried out within the monies received by HBDCA.</p>

Financial Review

<p>Review of the charity's financial position at the end of the period</p>	<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>
<p>Statement explaining the policy for holding reserves stating why they are held</p>	<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>
<p>Amount of reserves held as at 31st March 2025</p>	<p>£46,290.42</p>
<p>Other financial notes</p>	<p>HBDCA as received £1,050 in donations during the financial year</p> <p>HBDCA is now registered for VAT.</p>

Additional information

<p>A description of the principal risks facing the charity</p>	<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>
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	<p>committed to provide. HBDCA now has nine psychotherapists in its team as well as a part-time child psychologist.</p>
<p>In conclusion</p>	<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>
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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:**

Name:

Relevant professional qualification(s) or body (if any):

Address:

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

HBDCA

England & Wales - Charity number 1191416

Accounts

HBDCA

Annual Report and Financial Statements

Year ended 31st March 2024

Charity Number: 1191416

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Administrative details

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

HBDC A Organisational Structure

Trustees

Nina Beer

Governance and Fundraising

Joseph Peaty

Patient expert: Inhibitors and Infected Blood

Cynthia Creavalle

Finance

Maryam Samina

Patient expert: Ultra-rare bleeding disorders

Dr. Kate Khair

Medical expertise

Farid Gasanov

Financial 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 – joined 2023

Anita Smith (on ad hoc basis)

Psychotherapist – joined 2023

Jennifer Wainman

Psychotherapist – joined 2023

Eve Jones

Psychotherapist – joined 2023

Dr. Hannah Dunford

Child Psychologist – joined 2023

Patrick Browne
Associate Music Therapist

Aizat Adarbekova
Interpreter – Kyrgyz project

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

Christina Burgess

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	Maryam Samina			
5	Dr. Kate Khair			
6	Farid Gasanov			
7				
8				

Exemptions from disclosure

Reason for non-disclosure of key personnel details

N/A

The charity's organisational structure and any wider network with which the charity works

HBDCa is led by six trustees: the Chair, Nina Beer, Joseph Peaty, and Cynthia Creavalle, along with three newly elected trustees: Maryam Samina, Dr. Kate Khair and Farid Gasanov. HBDCa also has a wonderful ambassador, Ros Cooper.

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 nine-fold psychotherapeutic team and by the bleeding disorder community itself.

	<p>HBDCA works closely with the Haemophilia Department at the Royal London Hospital, the Haemophilia Department at the Kent and Canterbury Hospital, the Haemophilia Department at Oxford and by supporting patients at the Queen Elizabeth Hospital Birmingham Haemophilia Centre, providing psychological support to their patients, including family members.</p> <p>It 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 England Infected Blood Support Scheme (EIBSS).</p>
<p>Relationship with any related parties</p>	<p>HBDCA is an approved provider of psychological support for the Royal London Haemophilia Department, the Kent and Canterbury Haemophilia Department, Oxford University Hospital Haemophilia Department, along with Hammersmith, St George's, Tooting, Leeds, Nottingham, Addenbrookes and very soon Southampton. It also works with 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 and NHS England.</p>
<p>Other</p>	<p>HBDCA has had an increased involvement with Haemnet this year which carries out research within the bleeding disorder community. Haemnet was a key contributor to the Principles in Gene Therapy UK roundtable. HBDCA and Haemnet have had an NDA in place since July, 2022. Their Director of Research, Dr. Kate Khair has now been elected an HBDCA Trustee.</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, 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.</p>

HBDCCA Trustees' Annual Report

For the period: 01 April, 2023 To 31 March, 2024

Charity name: HBDCCA
(Haemophilia and Bleeding Disorders Counselling Association)

Charity registration number: 1191416

Objectives and Activities

<p>Summary of the purposes of the charity as set out in its governing document</p>	<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 to improve the support they provide to the bleeding disorder community.</p>
<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>	<p>The Royal London Hospital Haemophilia Department (RLH)</p> <p>Throughout this period, HBDCCA continued to support patients and family members at the Royal London Hospital Haemophilia Department (RLH). As anticipated, a new contract was renewed in August, 2023, for a longer-term, 5-year period which includes funding for a part-time child psychologist.</p> <p>The support provided by HBDCCA consisted of one-to-one psychotherapeutic counselling, themed wellbeing workshops, 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 Rare Peer Support Group which HBDCCA runs on a voluntary basis. There are now 11 members of this group from across the UK.</p>

HBDCa has been supporting 40 patients during this period, including 15 new patients, who had all been referred by the multidisciplinary team (MDT) at the RLH. Approximately 60 contact calls were made during this period, 15 pre-assessment sessions carried out and 250 psychotherapy one-to-one sessions completed.

The number of patients currently being supported equates to approximately 60% of those patients originally referred to HBDCa by the RLH. In addition, 3 further patients have successfully concluded their psychotherapy.

Any 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 workshops they might attend.

A planned Gene Therapy Wellbeing event has been delayed until the Haemophilia Department feels it is the right time in order for them to commence this new therapy first. It is anticipated this wellbeing workshop will now take place in early/mid 2025.

HBDCa was invited in March, 2024, to participate in the Royal London Haemophilia Department 5-year Peer Review for which it was interviewed about the psychological support it provides to patients there.

HBDCa continues to hold valuable conversations with the RLH 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. HBDCa is also working hard to promote greater understanding around issues experienced during perimenopause and menopause by women with bleeding disorders.

HBDCa has also commenced a conversation with the Royal London ITP (Immune thrombocytopenic purpura) Department with a view to providing psychotherapeutic support to their patients in a similar way to patients at the Haemophilia Department.

Continuing and new themes identified during psychotherapy sessions:

- 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.
- Patient empowerment, more specifically having a deeper understanding of their bleeding disorder and treatment plans.
- Importance of patient autonomy.
- 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.
- **This year a recurring theme has been the impact on people’s mental wellbeing from Infected Blood. The delay of the Infected Blood Public Inquiry Final Report which was originally due to be published in Autumn 2023 with the anticipated Report now due to be published in May 2024, has caused a great deal of distress, continued uncertainty and increased anxiety.**

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

HBDCA is now supporting 16 patients at the Kent and Canterbury Hospital Haemophilia for the long-term, having signed a two-year contract in April, 2023.

This provision affords a similar level of psychological support to K&C patients to that provided to patients at the Royal London.

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 workshop.

A community wellbeing day to celebrate World Haemophilia Day was held on 15 April, 2023. Thirty attendees participated from all cohorts within the bleeding disorder community there.

Two patients at the K&C continue to be members of the Rare Peer Support Group.

HBDCa was invited to participate in the K&C peer review in early 2024 and were interviewed about psychological provision at the Centre. As an outcome of this interview, HBDCa was recommended to meet with Addenbrookes Haemophilia Centre in Cambridge as a potential source of psychological provision to their patients.

N.B. As well as providing one-to-one psychotherapy, HBDCa also continues to carry out regular check-in calls with a small cohort of patients from the RLH and the K&C, who require this, due to their particular circumstances and issues which have imposed greater isolation on them all compared to most in the bleeding disorder community.

Statement from HBDCa Child Psychologist about her work with HBDCa including with children and young people from the K&C:

I have been working with those within the bleeding disorder community for around 5 years, the last year of which I have been involved with HBDCa. I truly believe the support that HBDCa provides to this community is invaluable and I feel privileged to be a part of this. Those I speak to that have been supported by HBDCa whether that is through 1-1 support, workshops or through the community support initiatives always tell me how much they and their extended families have benefitted and I know the charity is held in very high regard within the community. As a psychologist I am aware of the emotional and physical impact that having a long-term health condition has on an individual and those around them and I truly believe that HBDCa offers a lifeline to such individuals when they are unable to get the support they so desperately need from other services. HD

Oxford University Hospital Haemophilia Centre

HBDCa commenced a 1-year pilot with Oxford Haemophilia Centre on 1 March, 2024. A maximum of 10 patients will be supported over the year and two wellbeing days held. The proposed wellbeing day themes will be Transition and Women with Bleeding Disorders.

HBDCa will participate in the Oxford Centre's 5-year Peer Review in May, 2024.

The London Clinic

In February, 2024, HBDCa was asked to be the provider of psychological support to patients and family members of the first private Haemophilia clinic in the UK. This support is yet to commence but will be an additional route for HBDCa to make a further difference to the bleeding disorder community.

University Hospital Southampton Haemophilia Centre

It is anticipated that HBDCa will commence support for patients and family members at UHS in the coming year.

Support beyond One-to-One Therapy

In addition to individual psychotherapeutic support, with the peer support groups and wellbeing workshops held this year HBDCA has supported a further 120 people, including parents, children, siblings, grand-parents and partners from across all cohorts within the bleeding disorder community.

St George's Hospital 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).

Hammersmith Haemophilia Department - Imperial College Healthcare NHS Trust / Hammersmith Hospital

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. It is anticipated, funding allowing, that this partnership will commence fully in late 2024.

Birmingham Hospital Haemophilia Department - Haematology - University Hospitals Birmingham NHS Foundation Trust

Having been contacted by Birmingham Haemophilia Centre in late March, 2023. HBDCA commenced supporting, on an informal basis, whilst they continue to recruit a psychologist within the NHS, 8 patients at this Centre. This support commenced in May, 2023.

HBDCA Rare Peer Support Group

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 a rare bleeding disorder. It now has 11 members ranging in ages from early twenties to mid-seventies, including the mother of a young child with Glanzmann's Thrombasthenia.

The rare disorders range from Glanzmann's Thrombasthenia, Factor VII Deficiency and Bernard Soulier Disease. The women who attend this group continue to experience a great sense of isolation as well as issues around delayed diagnosis and treatment.

HBDCA continues to signpost this group to other Rare initiatives and also to keep them informed of any European Rare and Inhibitor Network (ERIN) activities they might like to participate in. This cohort has its 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.

Quote from a member of the Rare Peer Support Group:

Being a part of this group has been invaluable. Finding community in Blood Sisters and knowing I am not alone with my ultra-rare bleeding disorder along with having additional support and help through our WhatsApp group has been a much-needed addition to my life. Anonymous

The Terrence Higgins Trust/Macfarlane Trust Counselling Service (THT)

Having commenced support to the Infected Blood community in July, 2020, HBDCA still 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.

The client list for this vulnerable cohort continued to grow during 2023 – 2024 with HBDCA now supporting 15 people. 260 one-to-one psychotherapeutic sessions were provided to THT clients during this year.

During this period, HBDCA has carried out 4 peer support groups per month for the Infected Blood community. These meetings are virtual and facilitated by Christina Burgess. The meetings last on average 90 minutes each with 2 meetings per month for the Infected cohort and 2 meetings per month for the Affected cohort.

40 meetings were held between 1 April 2023 to 31 March, 2024.

Statement from a member of the ‘affected’ community:

This testimony is in support of the valuable work HBCDA has provided to support me to come to terms with and understand the decades of social isolation, stigma, prejudice and for myself, and I am sure others, including domestic abuse. When I contacted the Terrence Higgins Trust, I know now I had virtually given up and just wanted to know if there was anyone I could speak to to help me understand why and how my late partner had been infected with HIV? Understand why he chose never to tell me of his infection? So many why's? I hoped that as I am now in my later years of life, someone could help me that had lived through the horrors that were dealt to those infected by this deadly virus and why I was still alive and my partner was not? No one had ever explained anything to me. There was a wall of silence and secrecy. Outwardly no one could ever have imagined the suffering I was hiding, even from myself.

Sadly, when a person is vulnerable, isolated and with no one to care, or even miss them if they disappear, this makes them vulnerable to unscrupulous people. I was one of those people, this has given me a very different perspective on those on the streets, in prison and abandoned. If these people disappear from the face of the planet, there is no one to care or miss them. I felt I was more like them than any other group in society.

I was subsequently directed to HBCDA, who have supported me and given me a space to talk, with my counsellor Marion, who understands the problems faced by those infected and affected by the contamination of their loved ones by HIV. Without the support of Marion, I doubt I would still be here now.

Marion has helped me understand that I do matter. For the first time in decades I have felt that just maybe my life had a little worth. That I should not feel guilt for acknowledging I myself have needs and that I should look after myself, that I do matter. I had felt worthless and disposable any pleasure was from the happiness of others, not for myself. I had completely lost myself, the person I once was. I felt I was worthless, disposable and totally incapable of achieving anything.

It has taken a long time and hours of patience on the part of Marion. Only now am I just starting to speak about what happened to me. People like me become experts at hiding our feelings, due to ridicule and abuse.

The dedication, knowledge and commitment of Christina Burgess shines through her work. I cannot thank her enough for helping me at a time when I really felt all was lost, and as always was clinging to a grain of hope there was some justice left in the world.

Thanks to HBCDA just a tiny spark has been reignited that just maybe my views and feelings do matter, even if only the tiniest of ways.

*I am starting to feel the grief, pain and I would say delayed shock that I should have felt years ago, while this is devastating and painful, it is necessary to heal. I would never have come this far without HBCDA. **ML***

England Infected Blood Support Scheme (EIBSS)

From April 2023 to March 2024 HBDCA carried out nearly 200 psychotherapeutic therapy sessions for 12 clients, as well as completing pre-assessment sessions for each one.

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.

N.B. 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. Several hundred calls have been carried out to patients/clients by the Director in 2023 - 2024. These calls have increased especially due to the collective anxiety being experienced currently by the Infected Blood community.

Infected Blood Inquiry and community

HBDCA Director, Christina Burgess, has continued to attend Inquiry evidence days in person. Whilst attending the Inquiry she has been able to meet with a broad section of the Infected Blood community and with counterparts at other organisations such as The UK Haemophilia Society, Haemosexual and the Hepatitis C Trust.

2023 – 2024 has been a crucial time for the Infected Blood community and HBDCA is already aware of the impact on those it supports and the wider Infected Blood community as a whole. There are people who continue to experience renewed isolation now that the hearing days have been concluded. The length of the Inquiry (nearly 5 years) has also taken its toll. And for some, the anticipated outcomes from the Final Report and the government response to them are quite overwhelming and terrifying.

In order to ensure that HBDCA will be effective and at the top of its game to support such a vulnerable group of people, at the conclusion of the Infected Blood Public Inquiry, HBDCA has been preparing itself and the psychotherapeutic team to ensure that especially the psychotherapists have support mechanisms in place to enable them not to be overwhelmed or burnt out when the Inquiry concludes and the Final Report published. To this end, a team day was organised which took place in early March, 2024, and further support is being put in place to provide, throughout the coming year, additional Infected Blood supervision.

Quote from a member of the Infected Blood community:

I write to express my thanks for what has been overwhelming support with HBDCA providing such vitally important services.

I have received the most courteous and considerate care from you all. Anonymous

Statement from a key campaigner and member of the Infected Blood community:

HBDCa is the only psychological support service available with therapists uniquely qualified to support the bleeding disorder community. That has been the case throughout the six-year Infected Blood Inquiry. I attended two peer support days run by HBDCa this year and witnessed the power of victims finally opening up about the life altering experiences they'd had, in some cases for the first time in their lives. The bringing together of our infected blood community is a hugely effective and necessary therapeutic approach. The feedback I have had is overwhelmingly positive and more days are being requested. Particularly as we will navigate the next stage post the publishing of the Final Report, and undergo a period of judgement and assessment. Personally, I have turned to HBDCa for psychological help this year after damage caused by the inadequacies and complications of the proposed compensation scheme. The feelings of powerlessness and decisions about our lives being made by those who do not understand the impact reflects our original trauma. As we wait to find out what our lives mean in base financial terms with no clarity on when this will all be over, the compassionate and understanding HBDCa therapists are needed more now than ever. Anonymous

HBDCa Team-building Day, September 2023

HBDCa held its second team-building event which brought the team together, including trustees, to learn from each other, to share knowledge and information about bleeding disorders, to consider HBDCa's direction and focus in the coming year and, importantly, to further enhance the strong bond we all have with each other and further develop a joint sense of purpose in supporting the bleeding disorder community going forward. The event, funding permitting, will continue to be an annual event.

Statements from members of the HBDCa psychotherapeutic team on what their work and HBDCa means to them:

As a team moving into the latter stages of the inquiry we found ourselves considering how we might come alongside those in the community seeking support in a way that is honouring and helpful to the individuals we meet. As a team I felt that we were so deeply aware of the gravity of what some were to face both prior and post report. After some years of working in this community I was acutely aware that for many, they themselves felt uncertain of how they would feel as the inquiry drew to an end, unknowing in how to prepare themselves and their families for what was to come. As a therapist I was mindful that this was not going to be something that anyone could or maybe should predict. It has been my experience that whilst recognising that so many have indeed presented with a

complex tapestry of grief, pain, anger and loss, each and every person that I have had the privilege to meet with has their own unique story, a story that was so deeply worthy of bearing witness to.

Since spring as HBDCA moved into actively supporting more and more infected and affected individuals I have been reminded and humbled through my experiences of some of the most profoundly complex journeys towards healing and recovery. Christina our wonderful founder and guide here at HBDCA has reminded us over this time that this is likely to be just the beginning of a long path to recovery, something which now I understand so deeply when meeting with members of this community. For some this has been a lifetime of fighting, a lifetime of hiding themselves away, secrets and lies both interwoven and unfolding, the trauma has been relived and lived anew for far too many for far too long.

I know individually and as an organisation HBDCA will continue to strive towards providing a safe and trusted space for all those that contact us for support. LF

I have found the work we do with the HBDCA affected community can be life changing and is seen by clients as a step forward into their future. It provides a long-awaited space to communicate thoughts and feelings of loss, managing chronic health, being invisible and is something that the clients have needed for a long time. JW

The work of HBDCA allows a space for an often isolated and misunderstood community to feel seen and heard. Helping to provide a small part of this is incredibly rewarding and meaningful. EJ

Trustees

HBDCA trustee, Jackie Brooks, officially stepped down from HBDCA during the Team-building Day day. HBDCA showed Jackie appreciation of her contribution to HBDCA and its community by sending her flowers and a card in gratitude from the HBDCA team.

Three new trustees have been elected during this period. It had been decided to select trustees with particular expertise to further support the Director and HBDCA team in the complex work they do. The new trustees are: Maryam Samina – Ultra Rare Disorders, Dr. Kate Khair, Medical expertise and Farid Gasanov, financial and charity expertise. HBDCA is delighted to have them as part of the HBDCA team.

Trustees' Meetings

Trustees' meetings took place on:

27 April, 2023
19 July, 2023
17 September, 2023
18 October, 2023 (AGM)

13 December, 2023
22 March, 2024

HBDC A Psychology in Gene Therapy European Roundtable

Following on from the success of the 2023 UK roundtable conceived, organised and managed by HBDC A, on the topic of Principles of Psychology in Novel Therapies (Gene Therapy) the project was adopted in May, 2023 by EAHAD (European Association for Haemophilia and Allied Disorders) who felt that it would be important to create a set of European Principles of Psychology in Novel Therapies (Gene Therapy), rather than just UK-wide principles. A Europe-wide roundtable was therefore held at the EAHAD Congress in Frankfurt in February, 2024, with Christina Burgess being lead presenter and facilitator. More than 50 participants attended with the roundtable deemed a great success and much useful insight garnered. Currently two academic papers are being drafted by the EAHAD Psychosocial Committee which will form the next stage of creating the European Principles. At that Congress, Christina Burgess was elected Chair of the EAHAD Psychosocial Committee.

HBDC A website

Having had this work delayed due to the unavailability of the website professional tasked with carrying out this work, HBDC A is now in the process of updating its website to bring it completely up-to-date. Content to its website will reflect the different and diverse cohorts it works with and areas of work it carries out, such as Infected Blood.

HBDC A wishes to create a legacy page to reflect its past support for the IB community, and any future IB initiatives it will carry out. It believes it is important that there will be a record of this crucial and important work, and also in order to create a lasting tribute to this community and to ensure that the immense impact on this community is never forgotten.

There will also be sections on Women with Bleeding Disorders, Newly Diagnosed, Ageing and Long-term Pain, Ultra-Rare Bleeding disorders, Novel Therapies (Gene Therapy), and work in collaboration with the LGBTQ community. It will also highlight HBDC A's voluntary work and recognise further the team and the value they bring to HBDC A.

The HBDC A 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.

HBDC A Governance and Team Support

HBDC A continues to provide its psychotherapeutic team with monthly supervision sessions. This is especially important due to the work they carry out supporting people enduring deep trauma in the Infected Blood community. HBDC A recognised

	<p>that working in psychotherapeutic provision can be very impactful to the therapists themselves. Providing supervision is good practice and helps also 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 to, HBDCa's governance documents and policies. These meetings are ongoing.</p>
	<p>HBDCa Volunteer Project</p> <p>HBDCa has continued to facilitate 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>HBDCa continues to facilitate 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 also volunteer some hours per month each to support three very vulnerable people within the Kyrgyz community with (virtual) one-to-one psychotherapy. HBDCa is extremely grateful to these team members for continuing to give up their time and for providing such excellent, much-needed support. We are also very grateful to our contact in Kyrgyzstan, Aizat Aidarbekova, who acts as an interpreter for all our sessions. Without her, HBDCa would not be able to communicate with these clients. Strong bonds and trust have been forged with all three groups.</p> <p>Quote from member of HBDCa psychotherapy team:</p> <p><i>I was really pleased that I was able to make the meeting just before Christmas with the Kyrgyzstan group. It was very moving hearing a little bit about each of them and how their lives are impacted by haemophilia. It was also evident hearing from them all just how much the group meetings mean to them and how much of a lifeline they are in not feeling so alone in all they go through. I noticed just how much they loved and appreciated the work being carried out and how highly they spoke of Christina and the work of other members of HBDCa who have supported them. AF</i></p>
<p>Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit</p>	<p>The trustees of HBDCa adhere at all times to the principles and guidance issued by the Charity Commission on public benefit and apply these to all activities carried out by HBDCa.</p>

Achievements and Performance

<p>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>	<p>The Royal London Hospital Haemophilia Department</p> <p>HBDCAs 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 a part-time child psychologist now funding has been realised.</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 rare peer support group, HBDCAs intention is to bring these two cohorts together at least once a year at in-person meetings in the near future. 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>Comment from a senior member of the RLH multidisciplinary team:</p> <p><i>HBDCAs has been a fantastic asset to our Centre - they have provided a valuable service to the registered patients of our centre - regardless of diagnosis, needs or circumstance. The service has proved very easy to refer into, with a very fast response, most impressively where emergency psychological support was needed. All patient feed-back has been consistently very favourable. I can't thank the team enough for their engagement, dedication, care and support for both patients and for the team.</i></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 time in 30 years. HBDCAs believes that its deep insight into bleeding disorders and into infected blood, which it prides itself on being its USP (unique selling point), is essential in providing much-needed, long-awaited, effective psychotherapeutic support to this vulnerable group. With the anticipated Final Report and conclusion of the Infected Blood Public Inquiry now due to be published in May, 2024, the coming two years, post this date, will see this support needed more than ever.</p> <p>England Infected Blood Support Scheme (EIBSS)</p> <p>During the period 2023 - 2024 HBDCAs 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</p>
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	<p>counselling through the Terrence Higgins Trust/MacFarlane Trust route.</p> <p>Education and Information</p> <p>Through effective communication and by developing relationships with like-minded healthcare colleagues and organisations such as Haemnet, the HPA, EHC, EAHAD, 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 itself, 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 our healthcare professional colleagues across the MDT, about the psychological issues people with bleeding disorders and their family members experience.</p> <p>HBDCA has been able to share this psychotherapeutic knowledge and insight with the other organisations and colleagues it collaborates with.</p>
	<p>Team Meetings</p> <p>HBDCA continues to hold a weekly Zoom meeting with its therapy 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 ensure improved support for clients and patients.</p> <p>Wellbeing Events</p> <p>HBDCA is working towards ALL wellbeing workshops in the coming year being in-person events. However, it is conscious that resources may need to be allocated to providing greater support to the Infected Blood community during this crucial, upcoming year which may delay some workshops during this time.</p>

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HBDCA Strategic Plan 2023 – 2024

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 its patients, family members and carers

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

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

HBDCA will continue to support members of the Infected Blood community across the United Kingdom through the provision of specialist psychotherapy and by facilitating 4 monthly peer support groups. This will be especially important during 2024 due to the anticipated Infected Blood Final Report being published and the impact this will have on the Infected Blood community

HBDCA will use its insight and expertise to inform any new, bespoke Infected Blood psychological support service which will be set up by NHS England post the Infected Blood Public Inquiry

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 facilitation of a peer support group.

Achievements against objectives set in Strategic Plan 2023 - 2024	<p>HBDCA fully supports the Royal London Hospital Haemophilia Department across paediatric and adult patients and family members.</p> <p>HBDCA has continued to carry out work for St George’s Haemophilia Department, in Tooting, south London, with a formal agreement now in place to support patients at the Hammersmith Haemophilia Centre in the near future.</p>
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	<p>HBDCA continues to support patients and family members at the K&C and has commenced supporting patients and family members at Oxford University Hospital.</p> <p>HBDCA continues to provide support to 8 patients at Birmingham Haemophilia Centre, and on an ad hoc basis to other Centres, such as St George's, Tooting, Addenbrookes, Leeds and Nottingham, HBDCA will have fulfilled all elements of its 2023 – 2024 Strategic Plan.</p> <p>HBDCA continues to support, very effectively, the Infected Blood community across the United Kingdom through its work 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 as well as actively engaging with like-minded charities such as the UK Haemophilia Society, Haemosexual and the Hepatitis C Trust in advocating for the Infected Blood community. HBDCA has also, during this period, provided key knowledge, insight and information to the Infected Blood Inquiry itself on psychological issues and themes in order to positively inform the Infected Blood Final Report and its outcomes.</p> <p>Throughout this period, HBDCA continued to keep up to date with all outcomes of the Inquiry, attending many evidence days in person, including a special week in July 2023 where members of the government were called to provide insight into when compensation might be provided, especially to those in the 'affected community' who had at that stage not yet not been awarded interim compensation payments. Several individuals have been referred to HBDCA through the Public Inquiry itself. HBDCA also attended the UK Haemophilia Society Infected Blood Memorial Day in October, 2023.</p> <p>In July 2023, HBDCA was invited to become a member of the NHS England Stakeholder Group which will help inform the new, bespoke NHS psychological support service, which is being set up to provide psychological support to the Infected Blood community post the Final Report. HBDCA wrote to NHS England in July 2023 to request that all psychologists coming into this new service should be required to undergo rigorous, mandatory, in-person induction training. The letter was endorsed by the UK Haemophilia Society and the Hepatitis C Trust. Despite being a small charity, HBDCA hopes to influence, positively, the new NHS service, for the benefit of all people who will use it in the future.</p>
Investment performance against objectives	All the objectives achieved during the period 1 April 2023 – 31 March 2024, 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 £12,487 in its 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, 2023 – 31 March, 2024.</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 support it offers the bleeding disorder community.</p>
Amount of reserves held	<p>Reserves as of March 2024 amounting to £19,357 in total.</p>
Reserves	<p>HBDCA has carried out a financial forecast showing that it should be in a position to hold 6 months' reserves in the coming financial year, 2024 – 2025, and potentially up to 12 months' reserves in the following financial year,</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 therapists 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 committed to provide. HBDCA now has nine psychotherapists in its team as well as a child psychologist and a music therapist. HBDCA will address this issue further in 2024 - 2025.</p>
In conclusion	<p>HBDCA continues 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 itself, including during the team-building day and team-building lunch, as well as continuing to ensure that HBDCA governance documents and policies are fit for purpose.</p> <p>HBDCA benefits from a very committed, supportive and engaged group of Trustees 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 continued to work with 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>HBDCA has also continued to support the team itself and to provide more opportunities for learning and supervision, including Infected Blood supervision.</p>
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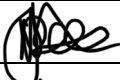
Structure, Governance and Management

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

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)	NINA BEER	
Position (eg Secretary, Chair, etc)	CHAIR	
Date	29.1.25	

HBDCA DIRECTOR'S REPORT 2023 – 2024

This period has been an exceptionally 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

During this year, after negotiations I was involved in were concluded, HBDCA was commissioned to work with a further Haemophilia Centre, Oxford, for a one-year pilot commencing on 1 March, 2024. We are also currently in talks with University Hospital Southampton Haemophilia Centre to support patients there. In addition, although HBDCA has not as yet commenced providing support to its patients, HBDCA has commenced working with the Hammersmith Haemophilia Centre.

HBDCA continues to support patients at Birmingham, and now, for the long-term, patients and family members at the Royal London Haemophilia Centre, and patients and family members for at least a further two years for the Kent and Canterbury Haemophilia Centre. I act as the main contact for all the Haemophilia Centres we work with and as liaison with the teams there.

HBDCA has also been approached to provide psychological support in the near future to 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, it 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. Having started our first wellbeing workshop in November, 2018, with three patients from the Royal London Haemophilia Department, we currently support approximately 150 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 but, due to the lack of funding for psychological support or a lack of psychologists within the NHS, 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 120 people, whether patients, clients, or family members, who might participate in wellbeing events, or in peer support groups or meetings we have participated in.

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 on several

occasions, being in a 'listening ear' capacity. Even when they may be receiving one-to-one psychotherapeutic support, each one of our patients and clients knows they can always reach out to have a call with me, should they need it. And, on HBDCA's behalf, I have written 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

As a demonstration of HBDCA's growth, we now have 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 has shown great commitment to the work HBDCA carries out. All our Trustees' input, expertise and insight has been invaluable, for which I am extremely grateful to them all.

Support for the psychotherapeutic team

It has been essential to ensure, given the HBDCA team is spread across the UK and beyond, that we provide valuable support, 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 for this vulnerable community.

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

With the anticipated publishing of the Final Report from the Infected Blood Public Inquiry on the horizon, having been delayed from Autumn 2023, then from Spring 2024, to now finally, May 20, 2024, HBDCA has witnessed, during this year, a great increase in anxiety, re-triggering of trauma, and fear of the future, from this community. The community is exhausted and nervous, and wary of the outcomes of the Report and how the government will respond to its recommendations.

Individuals and families have waited so long and have almost run out of steam during such a rollercoaster time, including with many people passing away this year, never having received the justice they deserved, the apology and acknowledgement they had 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 being witnessed by the team this year, as Director, I have been guiding the team and impressing upon them, in order to prepare them, that HBDCA

takes the view that the upcoming Final Report will not, as many people believe and hope, be the end of this long process of countless years, but the end of one phase and possibly the beginning of a more difficult phase, yet.

To this end, HBDCA held an IB (Infected Blood) event in Birmingham in March, 2024, to bring the team together in person, including HBDCA's Ambassador, Ros Cooper, who is from the Infected Blood community, herself, to devise a strategy as an outcome of this meeting, which will ensure the team is supported during this incredibly impactful time now and in the coming years, so that they themselves do not suffer burn-out and fatigue, once the Final Report is published. Thinking ahead, which will be reported on in next year's Trustees' Report and Director's Report, HBDCA has decided that it will be imperative to have a physical presence at the Final Report, in order to provide much-needed support throughout the key days surrounding the launch date, so this preparation of the HBDCA team in advance of this historical event has been essential.

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'. The support we provided has also continued to include four peer support groups (virtual) per month, two for the 'infected' cohort, and two for the 'affected' cohort, through funding from the Terrence Higgins Trust/MacFarlane Trust, which I facilitate. Although the numbers attending have been relatively small, the feedback from attendees, and their commitment to attend the meetings twice monthly, has demonstrated how invaluable these sessions have been during such a difficult and challenging time.

HBDCA also held a team-building day in early Autumn 2023 as an added layer of support for the HBDCA team. The team-building day has become an annual event, and 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 Psychological Support Service (IBPSS) which will be run by NHS England, will be fit for purpose and provide the highest level of psychological support possible. HBDCA's petitioning, including through Joseph and Ros, both from the Infected Blood community themselves, has tried to ensure, for instance, that rigorous, in-person inductions will be mandatory for all psychologists coming into this new and essential service. As a matter of course, HBDCA will 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 at least another year.

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. There are now 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.

EHC (European Haemophilia Consortium)

Running the Rare group (now in its third year) has enhanced the work I do as a newly elected member of the EHC ERIN (European Rare and Inhibitor Network) Committee, which evolved earlier this year from the IWG (Inhibitor Working Group) of which I had been a long-term member, since 2015. 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, and also existing and new treatments being tailored to provide effective care for them.

In March, 2024, I was also invited to be a member of a new EHC focus group on Mental Health. The aim is that we prove to the executive board at the EHC, our worth, so that the focus group will, in the coming year, become a fully-fledged Mental Health working group, which will go on to promote the need for greater mental health support provision, and increased awareness around mental health issues, for the bleeding disorder community across Europe.

Kyrgyzstan

I also continue to facilitate, more than two years' on, on a voluntary basis, with HBDCA's blessing, four monthly peer support groups for Kyrgyzstan, where, up until these meetings, no psychological or psychosocial support had been 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. Despite the language issue, there has been no barrier whatsoever, and the initiative has proved invaluable to this community. My aim, in the coming year, is to find funding for a small team from HBDCA to go to Kyrgyzstan to hold a number of in-person wellbeing events and to meet with some of the community who are greatly isolated, not just by living in remote, mountainous regions, but by the psychological isolation they experience through their bleeding disorder itself. It has been a privilege to work with 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.

EAHAD (European Association for Haemophilia and Allied Disorders)

As well as being a committed member of the EHC ERIN Committee, and having attended the EHC annual conference in Copenhagen in October, 2023, I also work with another European organisation: EAHAD. Having been a member of the EAHAD Psychosocial Committee since 2018, in early February, 2024, at the annual EAHAD Congress, in Frankfurt, I was honoured to be elected Chair.

The EAHAD Psychosocial committee, with the blessing of the EAHAD Executive Committee, adopted HBDCA's original UK-wide 2023 project which was to create Principles of Psychology in Novel Therapies (Gene Therapy). The EAHAD initiative, which was launched formally at the 2024 Congress, will now see these principles becoming European ones, and has enabled us, as the EAHAD Psychosocial Committee, to make this a key piece of work for the next two years, including the creation of two academic papers we hope to have published, with the hope that the EAHAD European Principles of Psychology in Novel Therapies, will be launched in 2025 – 2026. I was instrumental in developing and facilitating, as an outcome of the initial HBDCA UK Roundtable, a European roundtable at the Frankfurt Congress, which saw 50 attendees from across Europe, participate and contribute to the work we are doing. I was also a speaker during the Allied Health Professionals (AHP) Day during the Congress.

Other work

Other work I have contributed to as Director during this period has been to be interviewed as guest speaker for world-wide broadcast during World Haemophilia Week, for the pharmaceutical company, CSL Behring, to share with their employees across the world, the impact psychologically and psychosocially for the different cohorts within the bleeding disorder community.

I was also invited to write an article for the Nursing Times on the psychological and psychosocial issues experienced by women with bleeding disorders. The aim being to enable nurses to have more confidence when assessing whether their patient might be experiencing issues such as lack of self-confidence, fear of sharing their bleeding disorder diagnosis with a new partner or having to manage their bleeding disorder as a woman, when even female relatives might not believe them or support them.

Conclusion

The work carried out by myself as HBDCA Director, always has HBDCA at its core. Being a member of EAHAD and 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. At the 2024 EAHAD Congress, for instance, the buzz phrase throughout the Main Congress, not just at the AHP (Allied Health Professional) Day, was 'psychological support'. 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, as being an essential psychological entity when it comes to the provision of expert, improved mental wellbeing support which enables an enhanced quality of life 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, Eve Jones, Jennifer Wainman, Anita Smith, Dr. Hannah Dunford, Patrick Browne (music therapist), Aizat Aidarbekova (interpreter), Dr. Kerry-Ann Holder (supervision) and our great Accounts colleague, Emilia Bowzyk.

Thank you all, for enabling HBDCA to always go above and beyond and to punch above its weight. Through you all, HBDCA, as a tiny organisation, has had a great and positive, life-affirming impact for so many of the people we support.

THANK YOU.

Christina Burgess

Founder and Director

HBDCA

Independent Examiner's Report to the Trustees

For the year ended 31 March 2024

I report to the Trustees on my examination of the accounts of the charitable company for the year ended 31 March 2024.

Responsibilities and basis of report

The charity Trustees, who are also Directors for the purposes of company law, are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

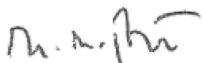
Independent examiners statement

I have completed my examination. I confirm that no 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 Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the requirements of section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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 to enable a proper understanding of the accounts to be reached.

Usama Butt



Statement of Financial Activities (including summary of income and expenditure Account)
Year ended 31 March 2024

		Unrestricted Funds £	Restricted Funds £	2024 Total Funds £	Unrestricted Funds £	Restricted Funds £	2023 Total Funds £
<u>Income and Charitable Activities</u>							
	Note						
Grants & Donations	6	105,114	(3,000)	102,114	63,115	30,000	93,115
<u>Expenditure on:</u>							
Raising funds	7	72,071	7,760	79,831	65,358	10,887	76,245
Charitable activities	7	12,055	114	12,169	12,108	8,867	20,975
Other	7	1,552	-	1,552	523	-	523
		<u>85,678</u>	<u>7,874</u>	<u>93,552</u>	<u>77,989</u>	<u>19,754</u>	<u>97,743</u>
Net (Expenditure)/Income		19,436	(10,874)	8,562	(14,874)	10,246	(4,628)
<u>Reconciliation of funds:</u>							
Total funds brought forwards		(601)	11,396	10,795	14,273	1,150	15,423
Total funds carried forwards	6	<u>18,835</u>	<u>522</u>	<u>19,357</u>	<u>(601)</u>	<u>11,396</u>	<u>10,795</u>

Balance sheet As at 31 March 2024	Note	March 2024	March 2023
Fixed assets	3	<u>532</u> 532	<u>-</u> -
Cash at bank in hand		35,989	12,487
Trade debtors	4	7,762	27,095
Other debtors	4	<u>9,018</u>	<u>1,578</u>
		52,769	41,160
Creditors: Amounts falling due with in one year	5	<u>33,944</u>	<u>30,365</u>
Total Net Assets		<u>19,357</u>	<u>10,795</u>
Restricted Income Funds	3	522	11396
Unrestricted Funds	3	<u>18,835</u>	<u>(601)</u>
		<u>19,357</u>	<u>10,795</u>

The charity was entitled to exemption from audit under Charities Act 2011 and trustees have not required the charity to obtain an audit in accordance with Charities Act 2011.

Trustees acknowledge their responsibilities for complying with the requirements of the Charities Act with respect to accounting records and the preparation of accounts.

These accounts have been prepared in accordance with the provisions applicable to charities under audit exemption regime and in accordance with FRS102 SORP.

The accounts were approved by the Trustees on 21st January 2025 and signed on their behalf by: -



Nina Janine Beer

Trustee

Notes to the financial statements

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

3 Tangible fixed assets		Computer equipment £
Cost or valuation		
At 1 April 2023		-
Additions		<u>709</u>
At 31 March 2024		<u>709</u>
Depreciation		
At 1 April 2023		-
Charge for the year		<u>177</u>
At 31 March 2024		<u>177</u>
Net book value		
At 31 March 2024		<u>532</u>
At 31 March 2023		<u>-</u>
4 Debtors	March 2024	March 2023
Amounts falling due within one year		
Trade debtors	7,762	27,095
Other debtors	9,018	1,578
	<u>16,780</u>	<u>28,673</u>
5 Creditors:	March 2024	March 2023
Amounts falling due with in one year		
Trade Creditors	-	634
VAT	9,853	-
Accruals	990	960
Deferred Income	21,167	26,250
Other creditors	1,934	2,521
	<u>33,944</u>	<u>30,365</u>

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.

6 Movement in Funds	At the start of the year	Incoming Resources	Outgoing Resources	At the End of the Year
Restricted Funds	11,396	(3,000)	7,874	522
Unrestricted Funds	(601)	105,114	85,678	18,835
Total Funds	10,795	102,114	93,552	19,357

7 Expenditure	Unrestricted Funds £	Restricted Funds £	2024 Total Funds £	Unrestricted Funds £	Restricted Funds £	2023 Total Funds £
<u>Expenditure on raising funds:</u>						
Staff & CEO fee	47,957	-	47,957	39,643	-	39,643
Management fee	21,620	7,760	29,380	22,841	5,350	28,191
Events - Hosted	2,494	-	2,494	2,874	5,537	8,411
	72,071	7,760	79,831	65,358	10,887	76,245
<u>Expenditure on Charitable activities:</u>						
Advertising & Marketing	-	-	-	-	1,101	1,101
Audit & Accountancy fees	3,915	-	3,915	4,419	-	4,419
Bank fees	50	-	50	-	-	-
Consulting	3,220	-	3,220	4,520	5,922	10,442
Telephone	1,793	-	1,793	774	-	774
Printing & stationery	200	-	200	146	-	146
Staff training	48	-	48	-	-	-
IT & Software	-	-	-	412	-	412
Travel & Subsistence	2,829	114	2,943	1,837	1,844	3,681
	12,055	114	12,169	12,108	8,867	20,975
<u>Other</u>						
Insurance	385	-	385	375	-	375
Sundry expenses	990	-	990	148	-	148
Depreciation	177	-	177	-	-	-
	1,552	-	1,552	523	-	523
	85,678	7,874	93,552	77,989	19,754	97,743

HBDCA

England & Wales - Charity number 1191416

Accounts



HBDCA

Annual Report and Financial Statements

Year ended 31st March 2023

Charity Number: 1191416

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Administrative details

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

HBDCA Organisational Structure

Trustees

Nina Beer

Governance and Fundraising

Joseph Peaty

Patient expert: Inhibitors and Infected Blood

Cynthia Creavalle

Finance

Jackie Brooks

Carers

Ambassador - Ros Cooper

Women 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

Associate

Anita Smith

Psychotherapist

Alicia Fowkes

Psychotherapist – joined January 2023

Patrick Browne

Associate Music Therapist

Name of chief executive or names of senior staff members

Christina Burgess

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 Paul Peaty			
3	Jacqueline Brooks			
4	Cynthia Creavalle			
5				
6				
7				
8				
9				
10				
11				

Exemptions from disclosure

Reason for non-disclosure of key personnel details

N/A

The charity's organisational structure and any wider network with which the charity works	<p>HBDCa is led by four trustees: the Chair, Nina Beer, along with Joseph Peaty, Jacqueline Brooks and Cynthia Creavalle who was elected in November, 2021. HBDCa also has an ambassador, Ros Cooper.</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 six-fold psychotherapeutic team and by the bleeding disorder community itself.</p> <p>HBDCa works closely with the Haemophilia Departments at the Royal London Hospital and Kent and Canterbury Hospital to provide</p>
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	<p>psychological support to their patients, including family members.</p> <p>It 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 (THT) and also to anyone infected either with HIV, Hepatitis C or co-infected with HIV/Hepatitis C through the England Infected Blood Support Scheme (EIBSS).</p>
Relationship with any related parties	<p>HBDCa is an approved provider of psychological support for the Royal London Haemophilia Department, Kent and Canterbury, the Terrence Higgins Trust Counselling Service and the England Infected Blood Support Scheme (EIBSS). It collaborates with The UK Haemophilia Society, Haemosexual, the HPA, Haemnet, the Hepatitis C Trust and the Kyrgyz NMO.</p>
Other	<p>HBDCa has had an increased involvement with Haemnet this year which carries out research within the bleeding disorder community. HBDCa invited Haemnet to be a key contributor to the Principles in Gene Therapy roundtable. HBDCa and Haemnet have had a Non-disclosure Agreement in place since July, 2022.</p> <p>The 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 such 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, 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.</p>

HBDC A Trustees' Annual Report

For the period: 1 April 2022 to 31 March 2023

Charity name: HBDC A
(Haemophilia and Bleeding Disorders Counselling Association)

Charity registration number: 1191416

Objectives and Activities

<p>Summary of the purposes of the charity as set out in its governing document</p>	<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>
<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>	<p>The Royal London Hospital Haemophilia Department (RLH)</p> <p>Throughout this period, HBDC A continued to support patients and family members at the Royal London Hospital Haemophilia Department (RLH) with the strong expectation that the new contract (which will be renewed in August, 2023), will be for a longer-term, 5 year period and will almost certainly include funding for a part-time child psychologist for which a business case was provided to support this in early 2023.</p> <p>The support provided by HBDC A consisted of one-to-one psychological counselling, quarterly, themed wellbeing workshops, 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 Rare Peer Support Group which HBDC A runs on a voluntary basis. There are now 10 members of this group from across the UK.</p> <p>HBDC A has been supporting 25 patients during this period, including 6 new patients, who had all been referred by the multidisciplinary team (MDT) at the RLH. Approximately 50</p>

	<p>contact calls were made during this period, 6 pre-assessment sessions carried out and 250 psychotherapy one-to-one sessions completed.</p> <p>The number of patients currently being supported equates to more than 50% of those patients originally referred to HBDCA by the RLH. In addition, 4 patients have successfully concluded their psychotherapy.</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 workshops they might attend.</p> <p>A (virtual) Empowerment and Pain Management Wellbeing Workshop was held on 13 November, 2022. This workshop was well received and will be held in person next year. Three further workshops were scheduled to be held this year on the following themes:</p> <ul style="list-style-type: none"> • Newly Diagnosed Families • Women with Bleeding Disorders • Gene Therapy. <p>The Gene Therapy Wellbeing event has been delayed until the Haemophilia Department feels it is the right time in order for them to commence this new therapy first. It is anticipated the wellbeing workshop will now take place in early/mid 2024.</p> <p>HBDCA intends to run all its wellbeing workshops in person at the Royal London from 2023 – 2024 and beyond. This has not been possible this year whilst the Haemophilia Centre has still continued to restrict visits to the Centre in person post the Covid-19 pandemic.</p> <p>HBDCA has also commenced valuable conversations with the RLH 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.
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- A heightened sense of isolation for women in the 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.
- 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.
- 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.

Quote from an RLH patient being supported by HBDCA:

'I am having counselling from HBDCA. If it wasn't for this counselling I would be in a very bad way. Especially as a medical procedure I was due to have was cancelled a number of times. They have helped me to be able to look forward to the future'.

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

From April 27, 2022, HBDCA commenced, as anticipated, the one-year pilot which provides a similar level of psychological support to K&C patients to that provided to patients at the Royal London.

During this time, HBDCA carried out 100 contact calls with patients/family members referred by the MDT, 16 pre-assessment sessions and provided 150 psychotherapeutic sessions to the 14 patients wishing to access support.

	<p>Quote from a member of the K&C MDT:</p> <p><i>'Thank you for all that you and your team do for people with bleeding disorders, it is very much appreciated and life-changing'.</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 three in-person wellbeing workshops on the following themes:</p> <p>Newly Diagnosed Families (NDF) 19 November 22</p> <p>Quote from a parent who attended the NDF workshop:</p> <p><i>'The therapists were so lovely, they really listened and were very caring. They offered support to both me and my husband. The only thing that could have been better was if more families had turned up. But, actually, it turned out fine as the event was more personal and relevant to us.'</i></p> <p>Women with Bleeding Disorders 25 February 23</p> <p>Needle-phobia (Adults and children) 25 March, 23</p> <p>Two patients at the K&C are now members of the Rare Peer Support Group.</p> <p>Statement from a K&C patient being supported by HBDCA:</p> <p><i>'I have been receiving help from HBDCA with one of your wonderful psychotherapists, Lisa. To say these sessions have improved my life would be an understatement. I have lived with haemophilia for 30 years and finding myself increasingly affected by the condition over the last decade, I can say that I was not in a good place when I was referred to your service.</i></p> <p><i>If I had not been offered the assistance of HBDCA, I may very well not have been around to write this email to you now. For me the assistance offered was life-saving. I now have a better outlook on life and strategies to cope.</i></p> <p><i>I have benefitted greatly from the services offered and have no doubt that there are other men in the same situation I found myself in, who would benefit also'.</i></p> <p>For the first time HBDCA is supporting a couple with joint psychotherapy due to their unique circumstances.</p>
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	<p>Quote from K&C couple:</p> <p><i>'Marion is very helpful when she calls us to talk through things'.</i></p> <p>N.B. As well as providing one-to-one psychotherapy, HBDCA has also carried out regular check-in calls 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, with the peer support groups and wellbeing workshops held this year HBDCA has supported a further 80 people, including parents, children, siblings, grand-parents and partners from across all cohorts within the bleeding disorder community.</p> <p>St George's Hospital Haemophilia Department</p> <p>Despite not having a formal agreement with the Haemophilia Department at St George's, Tooting, with whom HBDCA has worked informally for the past 2 years, continued 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).</p> <p>Hammersmith Haemophilia Department - Imperial College Healthcare NHS Trust / Hammersmith Hospital</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. It is anticipated, funding allowing, that this partnership will commence in early 2024.</p> <p>Birmingham Hospital Haemophilia Department - Haematology - University Hospitals Birmingham NHS Foundation Trust</p> <p>HBDCA was contacted by Birmingham Haemophilia Centre in late March, 2023. They had been struggling, and continue to struggle, to find a psychologist within their Trust to join their MDT. They, therefore, asked if HBDCA would consider supporting patients they have identified as having urgent need of psychological support, on a patient-by-patient basis. This is being discussed currently with the aim of commencing this support in May, 2023.</p>
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	<p>HBDCA 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 a rare bleeding disorder. It now has 10 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. HBDCA has been able to signpost this group to other 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 has provided a safe space and platform to meet other women with the same or other rare bleeding disorders who face the same daily challenges living with a rare bleeding disorder brings. It provides reassurance that you are not alone and also provides an opportunity to learn from each other about managing day to day living and bleeding episodes. I really value this group and feel it has helped develop a much-needed support network for women with rare bleeding disorders'.</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 2022 – 2023 with HBDCA now supporting 11 people. 220 one-to-one psychotherapeutic sessions were provided to THT clients during this year.</p>
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	<p>Very sadly, it must be noted that during this time one of our long-term THT clients from the Infected Blood community passed away.</p> <p>The impact this had on the psychotherapist and on the team itself has spurred HBDCA on to create written information on how to manage one's own sense of bereavement as a psychotherapist. This written content will be included in the Self-Care section of the HBDCA team handbook currently being developed. HBDCA believes that this information will help to support the team, especially in anticipation that there will inevitably be more deaths in the coming months and years of people we have grown to know well.</p> <p>Separately, having mutually agreed and identified that there was a need for this, THT has 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. These meetings are virtual and facilitated by Christina Burgess. The meetings last on average 90 minutes each with 2 meetings per month for the Infected cohort and 2 meetings per month for the Affected cohort.</p> <p>6 meetings have been held so far between 1 February, 2023 to 31 March, 2023.</p> <p>England Infected Blood Support Scheme (EIBSS)</p> <p>From April 2022 to March 2023 HBDCA carried out nearly 100 psychotherapeutic therapy sessions for 7 clients, as well as completing pre-assessment sessions for each one.</p> <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.</p> <p>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 third year with HBDCA. This is testament to the level of trust between these very vulnerable, complex clients and our expert psychotherapists.</p> <p>N.B. 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</p>
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	<p>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. Several hundred calls have been carried out to patients/clients by the Director in 2022 - 2023.</p> <p>A quote from a person supported by HBDCA through EIBSS:</p> <p><i>'Christina and her team have been like a lifeline to me. I seriously do not know how I would have coped during this time. Just being able to talk to someone and get so much off my chest without explaining myself or being scrutinised is the best medicine I could have asked for'.</i></p> <p>Infected Blood Inquiry and community</p> <p>HBDCA Director, Christina Burgess, has continued to attend Inquiry evidence days in person. Whilst attending the Inquiry she has been able to meet with a broad section of the Infected Blood community and with counterparts at other organisations such as The UK Haemophilia Society and the Hepatitis C Trust.</p> <p>Christina Burgess attended the Inquiry when Sir Robert Francis, QC (now KC), shared his report on the Compensation Framework, and how he and his team see it working. HBDCA, in the previous year, had petitioned Sir Robert to include psychological support to any person who might need it, as part of any compensation package agreed by the government. Psychological support has indeed been included, thankfully, although in what form that service will look like is not yet clear at this point.</p> <p>HBDCA also wrote to the Chair of the Inquiry, Sir Brian Langstaff, following his first Interim Report in the summer of 2022, to ensure that he would continue to advocate for all people, infected and affected, to be provided with urgent interim payments whilst the Inquiry is still ongoing, rather than just the two cohorts he had recommended in this first Interim Report.</p> <p>The second Interim Report was published in March, 2023, with Sir Brian petitioning the government to do just that, to provide interim payments to all cohorts. It is not yet clear how the government will respond.</p> <p>2023 – 2024 will be a crucial time for the Infected Blood community and HBDCA is already aware of the impact on those it supports and the wider Infected Blood community as a whole. There are people who already are experiencing renewed isolation due to the majority of hearing days now being concluded, so that they can no longer meet other people from the Infected Blood community in person. The length of the Inquiry (nearly 5 years currently) is also taking its toll on so many who are physically and emotionally</p>
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	<p>exhausted after more than 30 years of waiting. And for some, the anticipation is quite terrifying. It has been voiced to HBDCA that some people had subconsciously thought the conclusion of the Inquiry would bring them closure and bring back the loved ones they had lost, whereas they are beginning to realise that whatever outcomes there are: financial and psychological compensation, apology from government, a sense of justice being served, that their lives will not really change and the losses and sense of bereavement will not abate.</p> <p>In order to ensure that HBDCA will be effective and at the top of its game to support such a vulnerable group of people, HBDCA is already beginning to prepare itself and the psychotherapeutic team to ensure that, especially, the psychotherapists have support mechanisms in place to enable them not to be overwhelmed or burnt out when the Inquiry concludes and the Final Report published so that they can be as supportive as needed. The Final Report is anticipated to be published in Autumn 2023 and the Public Inquiry concluded with a government response to the findings expected soon after that.</p> <p>Quote from a key campaigner in the Infected Blood community:</p> <p><i>'As someone very active within the bleeding disorder community, I cannot stress enough how important HBDCA is. They not only provide the personalised support required but they start from a place of knowledge and validation. This helps to minimise further trauma and gives the team a unique approach to their clients. Offering the community a genuine opportunity to feel comfortable when recalling some of their darkest memories cannot be underestimated. It is why I feel so strongly about suggesting people speak to them.'</i></p> <p>Providing information for healthcare professionals</p> <p>HBDCA, was approached in early 2022 to be the lead facilitator in a CSL Behring (pharmaceutical company) funded project which will explore, at a roundtable, the inequality of healthcare provision for women and girls with bleeding disorders. The roundtable has been further delayed but is anticipated to be held in 2023 - 2024.</p> <p>Christina Burgess was asked to write an article for the Nursing Times, aimed at nurses and healthcare professionals, which was published in March, 2023. The article shared with nurses what they might need to be more aware of, from a psychological/psychosocial point of view, regarding the impact a bleeding disorder will have during a girl and woman's life stages: puberty, relationships, cultural issues, their journey with pregnancy and childbirth and the menopause.</p>
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	<p>HBDCa Team-building Week-end August, 2022</p> <p>HBDCa held its first team-building event. Its purpose was to bring the team together, including trustees, to learn from each other, to share knowledge and information about bleeding disorders, to consider HBDCa's direction and focus in the coming year and, importantly, to further enhance the strong bond we all have with each other and further develop a joint sense of purpose in supporting the bleeding disorder community going forward.</p> <p>The event was hugely beneficial and will become an annual event, funding permitting.</p> <p>Self-care Wellbeing Workshop for Parents and Carers for Local Families with Bleeding Disorders (LFwBD) charity – 11 March, 2023</p> <p>HBDCa facilitated a day-long wellbeing workshop at the Royal Foundation of St Katharine's in London for LFwBD. The day was very well-received and included sessions on mindfulness and self-care. It also allowed the participants to meet with each other and to share stories, experiences and useful tips/advice with each other, with the aim of increasing knowledge and self-awareness, reducing isolation and reinforcing the peer support network within LFwBD and publicising more widely, HBDCa and its services. There were 15 attendees.</p> <p>This event is to become an annual fixture between HBDCa and LFwBD. The HBDCa Director is a committee member of LFwBD, an organisation which shares a similar ethos to HBDCa around service to the bleeding disorder community and the provision of essential care initiatives, including around mental health.</p> <p>HBDCa Psychology in Gene Therapy Roundtable</p> <p>HBDCa was awarded a grant from CSL Behring to fund an HBDCa gene therapy initiative. Having previously been involved in the creation of European Principles of Inhibitor Management, a collaboration between the European Haemophilia Consortium (EHC) and European Association of Haemophilia and Allied Disorders (EAHAD), HBDCa had decided that it would be very beneficial for the gene therapy community if a similar set of Principles were created around access to psychology, as this is not available at every Haemophilia Centre.</p> <p>This grant enabled HBDCa to realise its intention to organise and facilitate a roundtable with attendees from across the UK from all disciplines within the MDT along with patient experts, a patient advocate organisation and bleeding disorder researchers. The topic discussed was how it might be possible to create a set of Principles of Psychology in Gene Therapy and what these principles</p>
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	<p>should include. The roundtable members would also, at this meeting, agree a plan for the coming 18 months in order to create and finalise those principles. Gene Therapy is a new treatment which is to be made available in the coming year to those who are eligible to receive it. It will require sound psychological support at each stage of a person's journey with it, and potentially for their family members also.</p> <p>The roundtable was held between 13 – 15 January, 2023, in Birmingham. 18 experts participated, including MDT members, the HBDCA team itself and psychologist colleagues who work in the NHS represented by the HPA (Haemophilia Psychologists Association). There was also additional written content shared at the meeting from healthcare professionals and academics working in gene therapy who were unable to attend the meeting in person but who wished to help inform the principles.</p> <p>A short film by a patient expert who had already undergone gene therapy was also shared with attendees, along with a Zoom discussion with Professor Emeritus, Ted Tuddenham, one of the pioneering haematologists who was instrumental in developing gene therapy treatment. The roundtable was very successful with everyone agreeing on the need for principles and what they should look like. A 20-page report was then created by HBDCA post the roundtable which was disseminated to all interested parties in February, 2023, with a view to progressing this project over the coming 18 months.</p> <p>European Association of Haemophilia and Allied Disorders (EAHAD)</p> <p>In her role as Vice-Chair of the EAHAD Psychosocial Committee, Christina had been asked to report back on the gene therapy roundtable to the Psychosocial Committee. The committee had stated it was very interested in this HBDCA topic.</p> <p>During the EAHAD Congress 2023 which was held in Manchester in early February, meetings were held between Christina Burgess and healthcare professionals who had attended the HBDCA roundtable. There was also an EAHAD Psychosocial Committee meeting following this. The outcome of all these meetings was that the EAHAD Psychosocial Committee, supported by EAHAD itself, decided that it would like to take the original HBDCA project which was to create UK Principles even further with the intention, during 2023 – 2024, to create European Principles of Psychology in Novel Therapies (Gene Therapy) instead. These Principles would, of course, also apply to the UK.</p> <p>It was therefore agreed that the EAHAD Psychosocial Committee would adopt this project as their key piece of work in the coming 18 months, with Christina Burgess, representing HBDCA, as the lead, with the intention of</p>
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	<p>holding a similar European roundtable at the next EAHAD Congress in Frankfurt in February, 2024. The finalised European Principles of Psychology in Novel Therapies (Gene Therapy) will be launched at the EAHAD Congress in February, 2025.</p> <p>The aim is that these European Principles will be something all Haemophilia Centres involved in gene therapy and other novel therapies will aspire to, with the potential that Centres who sign up to these principles would attain a kite mark of excellence in doing so.</p> <p>HBDCA is extremely proud to have been the instigator of this important project with the hope that it will bring enormous benefit from a 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 addition to this, at the February, 2023, Congress, Christina Burgess presented a session at the Allied Health Professionals' Day Psychosocial conference on the topic, 'The benefit of running peer support groups'.</p> <p>Two academic papers by the EAHAD Psychosocial Committee, which had both been in the review process last year, have now been published in the academic journal, <i>Haemophilia</i>. One paper addressed the need for increased psychological support at Haemophilia Centres across Europe, the other paper, of which Christina was lead author, was on the impact of Covid-19 on healthcare professionals and patients and what has been learnt from this experience to help inform psychological/psychosocial care during future pandemics.</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), facilitating peer support groups for the partners of people with an inhibitor.</p> <p>During this period, Christina Burgess shared with the HBDCA team outcomes and information on many aspects of work carried out by the EHC, including from webinars and roundtables, which has benefitted the team, helping to further develop their insight and expertise. This knowledge has also been shared with the wider community, for instance, during HBDCA wellbeing workshops.</p> <p>Christina Burgess, representing HBDCA, attended the EHC Conference in Copenhagen in October, 2022, where she helped facilitate inhibitor sessions and was a guest speaker at a symposium on psychological benefits as an outcome of Covid-19. She shared that the main benefit was that mental health and wellbeing had become much more widely</p>
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	<p>spoken about during the pandemic with people, including now, thankfully, many healthcare professionals and organisations, realising how essential it is to support people to have good mental health. This is especially relevant for the bleeding disorder community as physical and mental health go hand in hand and impact greatly on each other.</p> <p>At this time, the Inhibitor Working Group was merged into a new committee, ERIN (European Rare and Inhibitor Network) in order to provide people with rare bleeding disorders similar support to that which is now standard for the majority of people with inhibitors. Due to this change, the EHC Summit in December, 2022, at Barretstown, Ireland, was for the ERIN community. Christina Burgess facilitated a self-care wellbeing event as well as holding peer to peer support meetings for partners from both cohorts.</p> <p>As Christina Burgess's IWG term came to an end in December, 2022, she had to reapply for the new committee along with all the other members of the IWG. Christina Burgess was elected as a member of the new committee with a further three-year term.</p> <p>In 2022 Christina Burgess, again representing HBDCA, was invited to become a member of the EHC Think Tank which is made up of a group of experts and healthcare professionals to inform a long-term study on: <i>The unmet needs of mental health support across all areas in the bleeding disorder community</i>. This project is ongoing.</p> <p>The involvement of HBDCA, represented by Christina Burgess, in EAHAD and the EHC, has enabled the HBDCA psychotherapy team to have continued access to up-to-date information and current teachings. Either from a medical or treatment perspective through EAHAD, or through patient advocacy initiatives it might be asked to contribute to from a psychosocial perspective for the EHC. Information on new treatments and medical innovations ensures that the HBDCA team can be more knowledgeable when supporting patients who may be undergoing these new treatments. By HBDCA making a long-term contribution to the work of these organisations and having a physical presence at key events such as their annual conferences HBDCA's profile continues to increase along with its reputation as an expert provider of psychological services in the United Kingdom.</p> <p>Quote from Lisa Fowler, HBDCA Deputy Director and Governance Lead:</p> <p><i>'I feel that the involvement in both the EHC and EAHAD has been to a degree integral in continued development and awareness of haemophilia provision and care. The multi-disciplinary perspective has continued to offer a deepening understanding of the intricacies of patients'</i></p>
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	<p><i>experiences alongside the advancement of care through EAHAD's research projects which offer further recognition of protocols which may inform how we attend to clients in the room.'</i></p> <p>HBDC A website</p> <p>HBDC A is 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, Rare Bleeding disorders, Novel Therapies (Gene Therapy), and work on behalf of the LGBTQ community. It will also highlight HBDC A's voluntary work and recognise further the team and the value they bring to HBDC A.</p> <p>HBDC A intends, at a time in the future, post the conclusion of the Infected Blood Public Inquiry, possibly in 2024 - 2025, 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, and how needed, and how HBDC A has been able to participate in this provision.</p> <p>The HBDC A 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>HBDC A Governance and Team Support</p> <p>HBDC A continues to provide its psychotherapeutic team with monthly supervision sessions. This is especially important due to the work they carry out supporting people enduring deep trauma in the Infected Blood community. HBDC A recognised that working in psychotherapeutic provision can be very impactful to the therapists themselves. Providing supervision is good practice and helps also to ensure that the team feels valued and supported in the essential work they carry out.</p> <p>HBDC A 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 to, HBDC A's governance documents and policies. These meetings are ongoing.</p>
	<p>HBDC A Volunteer Project</p> <p>HBDC A has now fully commenced the 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. HBDCA is extremely grateful to these team members for giving up their time and for providing such excellent, much-needed support. We are also very grateful to our contact in Kyrgyzstan who acts as an interpreter for all our sessions. Without her, HBDCA would not be able to communicate with these clients. Initially, HBDCA was concerned that there would be a barrier to this work both due to language and the fact that it is remotely carried out, but this has proved to not be the case at all, with strong bonds and trust being forged with these groups.</p> <p>Funding permitting, the intention will be, in the next year or so, for HBDCA to visit Kyrgyzstan in person with its small team of volunteers to run three in-person psychological wellbeing events. During this visit HBDCA would also hope to seek out and meet with sympathetic psychologists from Kyrgyzstan who may be interested in becoming involved in bleeding disorder support there. HBDCA would continue to act as a trainer and mentor but with the aim that the Kyrgyz community will eventually take ownership of this project, itself.</p> <p>HBDCA believed when it originally commenced this project that it was important to give back to a country where there was no psychological support. In doing so, the hope had been that not only would the participants from Kyrgyzstan benefit, but that so too would the HBDCA team itself. This has proved to be correct with those in the HBDCA team who are involved in this initiative developing further skills and increased psychological insight through supporting these vulnerable cohorts. HBDCA hopes that the important work it has done so far will, in 2024 - 2025, gain the recognition of the World Federation of Hemophilia, with HBDCA's aspiration that the model it has created might then be used to provide effective, much-needed psychosocial support to other countries where there is an absence of this support also.</p> <p>Quote from Lisa Fowler, HBDCA Deputy Director and Governance Lead:</p> <p><i>'Having the opportunity to support individuals in the Kyrgyzstan project has been instrumental in deepening my awareness of the profound sense of loss that particularly mothers have faced in the haemophilia community. This piece of work has centred largely around complex trauma and grief that has almost certainly been compounding of the work I have been involved in with the contaminated</i></p>
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	<i>blood community who also present with such complex issues.'</i>
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	The trustees of HBDCA adhere at all times to the principles and guidance issued by the Charity Commission on 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 will benefit from the addition of a part-time child psychologist once the funding for this is approved, which is anticipated to be in the next financial year.</p> <p>Christina Burgess continues to have an NHS Smart Card, along with remote access to the RLH system.</p> <p>The Empowerment and Pain Management Wellbeing Workshop (virtual) was very well-received. So much so that an in-person wellbeing event on the same theme is intended to be held in the coming year. 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 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>Comment from a senior member of the MDT at the RLH:</p> <p><i>'This is brilliant work! I have finally had a chance to read your report and it highlights the amazing work you and the team have done over the last year.</i></p> <p><i>I look forward to continuing to work with you and the HBDCA team over the next five years'.</i></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 time in 30 years. This provision of high-quality, effective psychotherapeutic support is being made available through</p>
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	<p>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 anticipated Final Report and conclusion of the Infected Blood Inquiry due in Autumn, 2023, the coming two years, post these, will see this support needed more than ever.</p> <p>England Infected Blood Support Scheme (EIBSS)</p> <p>During the period 2022 - 2023 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.</p> <p>Education and Information</p> <p>Through effective communication and by developing relationships with like-minded 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 itself, 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 rare disorders, those undergoing gene therapy trials, and also our healthcare professional colleagues across the MDT, about the psychological issues people with bleeding disorders and their family members experience.</p> <p>HBDCA has been able to share this psychotherapeutic knowledge and insight with other organisations including some pharmaceutical companies who provide treatment, who might not have previously understood or had any great knowledge of this unique community's psychological issues.</p>
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	<p>Team Meetings post Covid-19</p> <p>HBDCa continues to hold a weekly Zoom meeting with its therapy 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 ensure improved support for clients and patients.</p> <p>Now that Covid-19 has diminished in its impact, HBDCa is working towards ALL wellbeing workshops in the coming year being in-person events.</p>
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HBDCa Strategic Plan 2022 - 2023

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

HBDCa will support members of the Infected Blood community across the United Kingdom

HBDCa will provide psychosocial support to the second London Centre and its patients, family members and carers

HBDCa will expand its reach to a further hub in another region of the United Kingdom

<p>Achievements against objectives set in Strategic Plan 2022 - 2023</p>	<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 continued to carry out work for St George's Haemophilia Department, in Tooting, south London, with an expectation also of supporting patients at the Hammersmith Haemophilia Centre in the near future.</p> <p>HBDCa, has now commenced support for patients at the Kent and Canterbury Hospital Haemophilia Department with a one-year pilot due to conclude at the end of April, 2023.</p> <p>Should the additional Centre, Birmingham, engage HBDCa to support its patients and family members, which is anticipated to commence in May, 2023, HBDCa will have fulfilled that element of its 2022 – 2023 Strategic Plan.</p>
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	<p>HBDCa continues to support the Infected Blood community across the United Kingdom very effectively through its work 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 as well as actively engaging with like-minded charities such as the UK Haemophilia Society and the Hepatitis C Trust in advocating for the Infected Blood community. HBDCa has also, during this period, provided key knowledge, insight and information to the Infected Blood Inquiry itself on psychological issues and themes in order to positively inform decisions which will affect this vulnerable group when the Inquiry concludes.</p> <p>HBDCa has continued to keep up to date with all the outcomes of the Inquiry, attending many evidence days in person, including being in attendance on the day the Compensation Framework was presented.</p>
Investment performance against objectives	All the objectives achieved during the period 1 April 2022 – 31 March 2023, 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 £741.99 in its account. This reduced amount was caused by a delay in payment of fees due to HBDCa in February and March, 2022. As mentioned in the 2021 – 2022 Report, a new system was agreed with the payor to ensure a similar delay in paying HBDCa would not occur in the future. At 31 March, 2023, HBDCa closed the period with a balance of £12,487.00 in its 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, 2022 – 31 March, 2023.</p>
Statement explaining the policy for holding reserves stating why they are held	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 of specialised psychological support it offers the bleeding disorder community.
Amount of reserves held	Reserves as of March 2023 amounting to £10,795.00 in total.
Reserves	HBDCa has carried out a financial forecast showing that it should be able to hold 6 months' reserves in the coming financial year, 2023 – 2024, and potentially up to 12 months' reserves in the following financial year.

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 therapists 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 committed to provide. HBDCA now has seven psychotherapists in its team and will address this issue further in 2023 – 2024, including with the anticipated addition of 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 itself, including during the team-building weekend, as well as 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 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>HBDCA has also continued to support the team itself and provide more opportunities for learning and supervision.</p>


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

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)	Nina Janine Beer	
Position (e.g., Secretary, Chair, etc)	Trustee	
Date	25/01/2024	

Independent Examiner's Report to the Trustees For the year ended 31 March 2023

I report to the Trustees on my examination of the accounts of the charitable company for the year ended 31 March 2023.

Responsibilities and basis of report

The charity Trustees, who are also Directors for the purposes of company law, are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiners statement

I have completed my examination. I confirm that no 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 Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the requirements of section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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 to enable a proper understanding of the accounts to be reached.

Approved on 25th January 2024



Haroon Ashfaq FCCA

Statement of Financial Activities (including summary of Income and Expenditure Account)
Year ended 31 March 2023

	Note	Unrestricted Funds £	Restricted Funds £	2023 Total Funds £	Unrestricted Funds £	Restricted Funds £	2022 Total Funds £
<u>Income and Charitable Activities</u>							
Grants & Donations	3	63,115	30,000	93,115	56,737	-	56,737
<u>Expenditure on:</u>							
Raising funds	4	65,358	10,887	76,245	29,078	-	29,078
Charitable activities	4	12,108	8,867	20,975	13,519	-	13,519
Other	4	523	-	523	615	-	615
		<u>77,989</u>	<u>19,754</u>	<u>97,743</u>	<u>43,212</u>	<u>-</u>	<u>43,212</u>
Net (Expenditure)/Income		(14,874)	10,246	(4,628)	13,525	-	13,525
<u>Reconciliation of funds:</u>							
Total funds brought forward		14,273	1,150	15,423	748	1,150	1,898
Total funds carried forward	3	<u>(601)</u>	<u>11,396</u>	<u>10,795</u>	<u>14,273</u>	<u>1,150</u>	<u>15,423</u>

Balance Sheet
As at 31 March 2023

	Note	March 2023	March 2022
Cash at bank and in hand		12,487	742
Trade Debtors		27,095	24,112
Other Debtors		1,578	-
		<u>41,160</u>	<u>24,854</u>
Creditors: amounts falling due with in one yaer	5	(30,365)	(9,431)
Total Net Assets		<u><u>10,795</u></u>	<u><u>15,423</u></u>
Restricted Income Funds	3	11,396	1,150
Unrestricted Funds	3	(601)	14,273
		<u><u>10,795</u></u>	<u><u>15,423</u></u>

The charity was entitled to exemption from audit under Charities Act 2011 and trustees have not required the charity to obtain an audit in accordance with Charities Act 2011.

Trustees acknowledge their responsibilities for complying with the requirements of the Charities Act with respect to accounting records and the preparation of accounts.

These accounts have been prepared in accordance with the provisions applicable to charities under audit exemption regime and in accordance with FRS102 SORP.

The accounts were approved by the Trustees on 25th January 2024 and signed on their behalf by: -

Nina Janine Beer



Trustee

Notes to the financial statements

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 16 July 2014 (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.

3 Movement in Funds

	At the Start of the Year £	Incoming Resources £	Outgoing Resources £	At the End of the Year £
Restricted Funds	1,150	30,000	19,754	11,396
Unrestricted Funds	14,273	63,115	77,989	(15,335)
Total Funds	15,423	93,115	97,743	9,217

4 Expenditure

	Unrestricted	Restricted	2023 Total £	Unrestricted	Restricted	2022 Total £
<u>Expenditure on raising funds:</u>						
Staff & CEO Fee	39,643	-	39,643	21,228	-	21,228
Management fee	22,841	5,350	28,191	7,850	-	7,850
Events - Hosted	2,874	5,537	8,411	-	-	-
	65,358	10,887	76,245	29,078	-	29,078
<u>Expenditure on Charitable activities:</u>						
Advertising & Marketing	-	1,101	1,101	4,875	-	4,875
Audit & Accountancy fees	4,419	-	4,419	1,650	-	1,650
Bank Fees	-	-	-	168	-	168
Consulting	4,520	5,922	10,442	-	-	-
Telephone & Internet	774	-	774	-	-	-
Printing & Stationary	146	-	146	-	-	-
IT & Software	412	-	412	2,263	-	2,263
Travel & Subsistence	1,837	1,844	3,681	4,563	-	4,563
	12,108	8,867	20,975	13,519	-	13,519
<u>Other</u>						
Insurance	375	-	375	-	-	-
Sundry expenses	148	-	148	615	-	615
	523	-	523	615	-	615
Total	77,989	19,754	97,743	43,212	-	43,212

5 Creditors: amounts falling due with in one yaer

	March 2023 £	March 2022 £
Trade Creditors	634	3,728
Accruals	960	-
Deferred Income	26,250	-
Other Creditors	2,521	5,703
	30,365	9,431

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.

HBDCA

England & Wales - Charity number 1191416

Accounts



HBDCA

Annual Report and Financial Statements

Year ended 31st March 2022

Charity Number: 1191416

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Administrative details

Charity name	HBDCA
Other name the charity uses	(Haemophilia and Bleeding Disorders Counselling Association)
Registered charity number	1191416
Charity's principal address	Current address since 31 March 2022 5, St Andrews House St Andrews Park Soham, Ely CB7 5GY Previous address: 3, St Matthews Gardens Cambridge CB1 2PH

HBDCA Organisational Structure

Trustees

Nina Beer

Governance and Fundraising

Joseph Peaty

Patient expert: Inhibitors and Infected Blood

Cynthia Creavalle

Finance

Jackie Brooks

Carers

Ambassador - Ros Cooper

Women 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

Associate

Anita Smith

Psychotherapist

Jon Stringer

Adult Peer Mentor/Patient Advocate

(on sabbatical this year due to family commitments)

Name of chief executive or names of senior staff members

Christina Burgess

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	Jacqueline Brooks			
4	Cynthia Creavalle		From Nov 2021	
5				
6				
7				
8				
9				
10				
11				

<p>The charity's organisational structure and any wider network with which the charity works</p>	<p>HBDCa is led by four trustees: the Chair, Nina Beer, along with Joseph Peaty, Jacqueline Brooks and Cynthia Creavalle who was elected in November, 2021. HBDCa also has an ambassador, Ros Cooper.</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 six-fold psychotherapeutic team and by the bleeding disorder community itself.</p> <p>HBDCa works closely with the Haemophilia Department at the Royal London Hospital to provide psychological support to their patients, including family members.</p> <p>It 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 (THT) and also to anyone infected either with HIV, Hepatitis C or co-infected with HIV/Hepatitis C through the England Infected Blood Support Scheme (EIBSS).</p>
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Relationship with any related parties	<p>HBDCa is an approved provider of psychological support for the Royal London Haemophilia Department, the Terrence Higgins Trust Counselling Service and the England Infected Blood Support Scheme (EIBSS). It collaborates with The UK Haemophilia Society and with the HepC Trust.</p>
Other	<p>HBDCa has had an increased involvement with Haemnet this year which carries out research within the bleeding disorder community. As well as HBDCa being involved in providing insight through the review of academic papers on behalf of Haemnet on the psychological impact of bleeding disorders, HBDCa has also continued to learn from some of the research carried out by Haemnet. For instance, on the many issues and impacts experienced by women with bleeding disorders and research projects involving the rare bleeding disorders community.</p> <p>In addition to the above, Haemnet and HBDCa expect to collaborate in three areas of work in the coming year: gene therapy, women with bleeding disorders and rare bleeding disorders.</p> <p>This 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.</p>

HBDCA Trustees' Annual Report

For the period: 1 April 2021 to 31 March 2022

Charity name: HBDCA
(Haemophilia and Bleeding Disorders Counselling Association)

Charity registration number: 1191416

Objectives and Activities

<p>Summary of the purposes of the charity as set out in its governing document</p>	<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>
<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>	<p>The Royal London Hospital Haemophilia Department (RLH)</p> <p>From 1 April, 2021, HBDCA continued to negotiate with the Royal London with regard to its formal return to the Haemophilia Department. The final negotiations and contract were eventually signed in August, 2021, with HBDCA commencing psychological support to RLH patients from 1 September. The contract was for 1 year with the strong expectation that this contract will be renewed in 2023 for a longer-term, possibly 3 – 5 year contract. A longer-term contract had been anticipated to commence in 2022 but, due to the RLH team member responsible for these negotiations being absent for a long period of time, in order to ensure continuity, the one-year contract was agreed to, due to time constraints, but with the tacit</p>

	<p>agreement that the contract from 2023 onwards will be a long-term one.</p> <p>From 1 September, 2021 to 31 March, 2022, the support provided by HBDCA consisted of one-to-one psychological counselling, quarterly, themed wellbeing workshops, and the facilitation of peer support groups for male adults with a bleeding disorder and facilitation of a peer support group for women with bleeding disorders.</p> <p>Pre-assessment of patients and their being assigned to psychotherapists did not commence until November/December 2021 to ensure all HBDCA psychotherapy team members and the HBDCA Director had completed mandatory RLH training prior to this.</p> <p>25 patients were then initially referred by the multidisciplinary team (MDT) at the RLH.</p> <p>6 out of this group felt they did not require psychological support at this stage but were interested in peer support and wellbeing workshops. These patients were made aware that they can reach out for support to HBDCA at any time.</p> <p>19 pre-assessment sessions were carried out with patients then receiving one-to-one psychotherapeutic support during this period.</p> <p>60 psychotherapy sessions were carried out for these patients January – March, 2022.</p> <p>2 additional patients were assessed and then identified by HBDCA as requiring more in-depth psychiatric care.</p> <p>A Newly Diagnosed Families Wellbeing Workshop was held 26 March, 2022. Three further workshops were scheduled to be held in the coming year on the following themes:</p> <ul style="list-style-type: none">• Women with Bleeding Disorders• Empowerment and Pain Management• Gene Therapy.
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	<p>Some themes identified during psychotherapy sessions:</p> <p>Loss, and adjustments to a new sense of self and identity</p> <p>Patient empowerment, more specifically having a deeper understanding of their bleeding disorder and treatment plans</p> <p>Importance of patient autonomy</p> <p>Death anxiety - Having a chronic condition in the family tends to increase fears related to dying so counselling can help with proportionality regards anxiety around dying</p> <p>Limiting beliefs - Clearly having a physical disability may limit some activities however it has been noticed that it may be accompanied by limiting beliefs on potential overall. Counselling can help distinguish which limits the health challenge presents and which are self-imposed</p> <p>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 so that they can get their needs met and apply for support without feeling victimised by circumstance</p> <p>Permission - One particular piece of work centred on a patient giving themselves permission to have autonomy through understanding that they too are the expert, the expert on themselves. This led to a more collaborative feeling and a decrease in anxiety</p> <p>Feelings of disconnectedness since Covid hit</p> <p>Patients speak more about current personal issues, family dynamics than their disorder</p> <p>Patients have expressed that it is very helpful knowing that we, as HBDCA, have knowledge/understanding of haemophilia and that they can explore these feelings/anxieties</p>
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	<p>It is helpful to have somewhere to say exactly how they feel as they do not want to share/burden others with these thoughts.</p> <p>The Kent and Canterbury Hospital Haemophilia Department (K&C)</p> <p>In September, 2021, HBDCA commenced contractual talks with the K&C with a view to HBDCA providing a similar level of psychological support to its patients to that provided to the Royal London. It was agreed that a one-year pilot should ensue. Due to governance requirements, this pilot, which was initially anticipated to commence in late Autumn, 2021, will now commence in the new financial year at the end of April, 2022.</p> <p>In anticipation of HBDCA's commencement at the K&C, HBDCA provided psychotherapeutic support in late 2021 and early 2022 to three patients from the K&C who had been identified as being in urgent need of psychological support.</p> <p>St George's Hospital Haemophilia Department</p> <p>Despite not having a formal agreement with the haemophilia department at St George's, Tooting, HBDCA was requested by members of the multidisciplinary team (MDT) there to carry out psychotherapeutic crisis support (6 sessions) for one patient as well as a single 'listening ear' session for another patient. HBDCA also provided a letter for one of the patients it had assessed in order for them to apply for funding from the England Infected Blood Support Scheme (EIBSS). It is hoped that this adhoc support for St George's will become more formalised in the near future should adequate funding become available.</p> <p>University Hospital Southampton Haemophilia Department (UHS)</p> <p>HBDCA was invited to meet in person on 24 March, 2022, with the senior team at the UHS Haemophilia Department. They were exploring the possibility of HBDCA providing psychological provision to their patients, again along the lines of that provided to the Royal London. This</p>
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	<p>conversation is currently ongoing whilst funding is secured and put in place.</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 2021 – 2022 with HBDCA supporting 11 people. 203 one-to-one psychotherapeutic sessions have been provided to date for THT clients.</p> <p>England Infected Blood Support Scheme (EIBSS)</p> <p>From April 2021 to March 2022 HBDCA carried out 30 psychotherapeutic sessions for three clients, as well as completing a pre-assessment session for each one.</p> <p>In addition to providing this psychotherapeutic support, 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 these clients to be awarded funding by EIBSS.</p> <p>Originally, it was not certain if the EIBSS funding of £900 per client was a one-off award, but it has been confirmed that clients may re-apply should further support be required, on an annual basis. The change during this period has been in the fact that EIBSS clients are now beginning to apply for this further funding which will see an increase in HBDCA's work with this client-base during the coming year.</p> <p>N.B. It is important, for the recording of HBDCA's work and output during this period, to note that each client, whether from the Haemophilia Centres, from THT or</p>
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	<p>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. Several hundred calls have been carried out to patients/clients by the Director in 2021 - 2022.</p> <p>Needlephobia Workshop for Local Families with Bleeding Disorders (LFwBD) charity</p> <p>As mentioned in the previous Trustees' Report, the pharmaceutical company, Chugai/Roche, awarded an educational grant of £1500 to HBDCA on 26 March, 2021 to carry out a virtual needle-phobia workshop for families from LFwBD. It took place on 29 May, 2021. The needle-phobia workshop which had elicited interest from additional haemophilia departments such as at Leeds, provided valuable insight and coping strategies and tools to the participants. A morning session was held for parents and an afternoon session held for children. Our art psychotherapist, Anila Babla, worked with the children to create 'superpower' masks for them to wear and be used as a psychological tool to help them overcome fear of needles. We also had a young person speak to the children about his own experiences with needles in order to reassure them. 100% of those who attended stated that the workshop was helpful and insightful. HBDCA, funding permitting, aims to hold further needle-phobia workshops in the future.</p> <p>Infected Blood Inquiry and community</p> <p>HBDCA Director, Christina Burgess, attended several Inquiry evidence days in person. These days were not only essential in helping HBDCA to gain further insight into the trauma and issues experienced by the Infected Blood cohort, but also enabled Christina Burgess to meet with a broad section of the Infected Blood community and with counterparts at other</p>
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	<p>organisations such as The UK Haemophilia Society and the HepC Trust.</p> <p>An important piece of work was carried out by HBDCA during this period. It saw HBDCA supplying to Sir Robert Francis QC (now KC) and his team, a written submission to help inform their draft study on the Compensation Framework. HBDCA's submission outlined why psychological support should be provided as standard to anyone in the Infected Blood community, infected or affected, should they require it, as part of the final compensation package to be offered post-Inquiry. (The Infected Blood Inquiry is anticipated to conclude in 2023). HBDCA was notified, on receipt of its submission, that Sir Robert Francis's team were very grateful for the content of HBDCA's report and would use this valuable insight not only to inform the study and its outcomes, but also to inform their wider work around the Inquiry itself.</p> <p>Providing information for healthcare professionals</p> <p>Christina Burgess, Director of HBDCA, was approached in early 2022, further to the original CSL Behring BDA (Bleeding Disorders Academy) podcast held in the previous year aimed at nurses, to be the lead in a CSL Behring funded project, which will explore, at a roundtable, the inequality of healthcare provision for women and girls with bleeding disorders. This project will be aimed at healthcare professionals and used to highlight to politicians and government health departments the inequality experienced, for instance, around late diagnosis of girls and women. Having worked on the initial concept in early 2022, the roundtable has been delayed but is anticipated to be held in the coming year.</p> <p>European Association for Haemophilia and Allied Disorders (EAHAD)</p> <p>In February, 2022, Christina Burgess was elected Vice-Chair of the European Association for Haemophilia and Allied Disorders (EAHAD) Psychosocial Committee. (The original working group of which Christina was secretary had been</p>
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	<p>promoted to committee status at that point due to the efficacy of their work in improving access to psychosocial support across Europe being recognised by the EAHAD Executive Committee).</p> <p>Christina Burgess chaired sessions at the Allied Health Professionals' Day Psychosocial Conference at the EAHAD Annual Congress in February, 2022. The theme was: 'Transitions', covering transition for young people changing from paediatric to adult care, transition for patients to new treatments (i.e. gene therapy), and transition for psychosocial professionals to new measurement tools.</p> <p>European Haemophilia Consortium (EHC)</p> <p>Christina Burgess continued during 2021 – 2022 in her capacity as a long-standing member of the EHC Inhibitor Working Group, facilitating peer support groups on the EHC's behalf, for the partners of people with an inhibitor. She was also a key facilitator at the annual Inhibitor Summit in December, 2021 (virtual).</p> <p>As an added means of keeping the HBDCA team updated and informed, particularly around new treatments and on multidisciplinary advances, Christina Burgess has shared with the HBDCA team outcomes and information on many aspects of work carried out by the EHC, including from webinars and roundtables, which has benefitted the team, helping to further develop their insight and expertise. This knowledge has also been shared with the wider community, for instance, during HBDCA wellbeing workshops.</p> <p>HBDCA website</p> <p>HBDCA has, during this period, kept its website up to date not only to promote HBDCA but also to signpost people to other useful links or organisations. HBDCA is currently in the process of adding further content to its website to reflect the different cohorts it works with and areas of work it carries out, such as Women with Bleeding Disorders, Newly Diagnosed, complementary therapies (i.e. Music Therapy and Art Psychotherapy), plus a My</p>
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	<p>Stories section with insightful articles with a psychosocial focus from siblings, other family members, the Infected Blood community and from the bleeding disorder community as a whole.</p> <p>The HBDCA website, which is an extension of the team and the work being carried out, is a useful resource for the community.</p> <p>HBDCA Governance and Team Support</p> <p>Since early 2022 HBDCA has been providing its psychotherapeutic team with a monthly supervision session. This is especially important due to the work they carry out supporting people enduring deep trauma in the Infected Blood community. HBDCA recognised that working in psychotherapeutic provision can be very impactful to the therapists themselves. Providing supervision is good practice and helps also to ensure that the team feels valued and supported in the essential work they carry out.</p> <p>HBDCA has also set up a monthly Leadership meeting between the Director and the Senior Associate psychotherapeutic team, with a remit to continually improve, update, and add to, HBDCA's governance documents and policies. These meetings are ongoing.</p>
HBDCA Volunteer Project	<p>In March, 2022, HBDCA commenced a volunteer project with the Haemophilia and Bleeding Disorders community in Kyrgyzstan. It had been realised that there was no psychological support available at all to this vulnerable community. HBDCA ran a wellbeing workshop to launch this initiative. As an outcome of the workshop it is anticipated that HBDCA will facilitate peer support groups for three different groups: Single Mums, Parents of Newly Diagnosed Children and Young Adult Men with Haemophilia, on a voluntary basis, in the coming year, which will be reported on in the next Trustees' Report, 2022 – 2023.</p>
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	<p>The trustees of HBDCA adhere at all times to the principles and guidance issued by the Charity Commission on public benefit and apply these to all activities carried out by HBDCA.</p>

Achievements and Performance

<p>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>	<p>The Royal London Hospital Haemophilia Department</p> <p>Despite the delay in HBDCA's formal return to the Royal London Haemophilia Department, which had been anticipated for 1 April 2021, with the commencement actually being 1 September, 2021, the work carried out there since then has seen the patient numbers grow and the relationship with the multidisciplinary team develop very positively.</p> <p>At the start of the new contract, Christina Burgess was encouraged to apply for an NHS Smart Card, which she was successful in being awarded, which enables her to access the RLH system in-house and also remotely, so that she can view patient records and input into them.</p> <p>Separately to this, the entire HBDCA team were required to complete a comprehensive series of training modules, prior to commencement of psychotherapeutic support for patients. All modules were carried out successfully and were useful learning tools for the HBDCA team.</p> <p>The Newly Diagnosed Families Wellbeing Workshop was well-attended and successful, with several more being planned. Two peer support groups: Adults with a Bleeding Disorder, and Women with Bleeding Disorders commenced in March, 2022. These are being held on a monthly basis. The long-term benefits of these peer support groups will be reported in the next Trustees' Report, 2022 – 2023.</p> <p>Comment from a senior member of the MDT at the RLH:</p> <p>'Please pass on my heart-felt thanks to all the HBDCA team. I know how valuable you all are to our patient cohort from the first-hand feedback I have heard from many who have used your service. The service was long overdue at The Royal</p>
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	<p>London and I am sure it will continue to be a foundation of care going forward.’</p> <p>Additionally, HBDCA has been a key contributor to ongoing discussions with the Royal London MDT which will hopefully improve how psychological support is provided, and at what stages, to women and girls considering motherhood, going through pregnancy and also during the post-natal period.</p> <p>.</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 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.</p> <p>England Infected Blood Support Scheme (EIBSS)</p> <p>Since commencing psychological provision through EIBSS, during the period 2021 - 2022 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.</p> <p>Below is a quote from one of the clients HBDCA supports in the Infected Blood community:</p> <p>‘I cannot recommend HBDCA highly enough. They are all so warm and understanding. I have been having therapy sessions for a while now and it is like talking to a friend. I am a very anxious person and I was very scared to start my counselling journey but Christina and Lisa</p>
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	<p>have made me feel completely at ease and I am able to discuss anything with them, without judgment. Thank you both so much for everything.'</p> <p>Education and Information</p> <p>Through effective communication and by developing relationships with like-minded healthcare colleagues and organisations such as Haemnet, Haemosexual, The UK Haemophilia Society, the HepC Trust and the charity, Local Families with Bleeding Disorders, along with listening to the community itself, HBDCA has been able to reach out to, and inform, not only those infected and affected by a bleeding disorder but also the wider community, about the psychological issues people with bleeding disorders and their family members experience.</p> <p>HBDCA has also been able to share this psychotherapeutic knowledge and insight with healthcare professionals and other organisations including some pharmaceutical companies who provide treatment, who might not have previously understood or had any great knowledge of this unique community's psychological issues.</p>
Continuing impact of Covid-19	<p>Covid-19 psychological impact on healthcare professionals and patients</p> <p>The small EAHAD study on <i>'the impact of Covid-19 on healthcare professionals and patients'</i> carried out by Christina Burgess in 2020, has been used in 2021 – 2022 to inform the content of a Letter to the Editor from the EAHAD Psychosocial Committee, for the academic journal, <i>Haemophilia</i>. The Letter is currently being reviewed for publication.</p> <p>Commenced at the start of the Covid-19 pandemic, HBDCA continues to hold a weekly Zoom meeting with its therapy team, and regular Zoom meetings with the Trustees. This is an important part of the HBDCA culture which believes that supporting one's team and colleagues ensures improved support for clients and patients.</p> <p>Despite the pandemic being effectively over there are impacts still being</p>

	<p>experienced even in practical terms such as Haemophilia Departments preferring that psychotherapeutic support be provided virtually rather than in person. This virtual provision has been proven to be entirely effective but HBDCA is working towards a return to in-person wellbeing workshops in the coming year.</p> <p>HBDCA has also reflected and learnt from a further impact of the pandemic which is that many people were experiencing 'Zoom' fatigue. Now that the world is beginning to function in a pre-pandemic way once more, HBDCA will address this 'virtual' fatigue by holding more in-person psychotherapeutic support meetings and events in the coming year, 2022 – 2023.</p>
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HBDCA Strategic Plan 2021 - 2022

<p>HBDCA will provide effective, high-quality, tailored psychosocial support to patients, their family members and carers at The Royal London Hospital Haemophilia Centre</p> <p>HBDCA will support members of the Infected Blood community across the United Kingdom</p> <p>HBDCA will provide psychosocial support to the second London Centre and its patients, family members and carers</p> <p>HBDCA will expand its reach to a further hub in another region of the United Kingdom</p>
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<p>Achievements against objectives set in Strategic Plan 2020 - 2021</p>	<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 carried out work for St George's Haemophilia Department, in Tooting, south London, with the hope that this workstream will increase in the near future.</p> <p>HBDCA continues to support the Infected Blood community across the United Kingdom very effectively through its work with the Terrence Higgins Trust/MacFarlane Trust counselling service and through the England Infected Blood Support Scheme (EIBSS). HBDCA has also demonstrated support for this community</p>
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	<p>through actively engaging with like-minded charities such as the UK Haemophilia Society and the HepC Trust.</p> <p>It has also kept up to date with all the outcomes of the Inquiry, attending many evidence days in person. HBDCA submitted essential insight and evidence which was used to inform the Infected Blood Compensation Framework. N.B. The initial draft of the framework study has stated that it recognises the need for psychological support (point 17 in its recommendations).</p> <p>HBDCA, during this period, commenced contractual negotiations with the Kent and Canterbury Hospital Haemophilia Department with its imminent presence expected in the new financial year, April, 2022, achieving a further key objective of the 2021 – 2022 Strategic Plan.</p>
Investment performance against objectives	All the objectives achieved during the period 1 April 2021 – 31 March 2022, were carried out within the monies received by HBDCA.

Financial Review

<p>Review of the charity's financial position at the end of the period</p>	<p>HBDCA commenced the period with £1897.69 in its account and ended the period with £741.99 in its account. This reduced amount was caused by a delay in payment of fees due to HBDCA in February and March, 2022 with a further amount of £5,832 anticipated to be received before the year end. In the event, these additional monies arrived into the HBDCA account on 11 April, 2022, and will be included in next year's Trustees Report and the accompanying Financial Return. Had these monies arrived on time the balance would have been: £6,574.00. Please note: a new system has been agreed with the payor to ensure a similar delay in paying HBDCA will not occur in the future.</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, 2021 – 31 March, 2022.</p>
<p>Statement explaining the policy for holding reserves stating why they are held</p>	<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 support it offers the bleeding disorder community.</p>
<p>Amount of reserves held</p>	<p>None.</p>
<p>Reasons for holding zero reserves</p>	<p>As explained above.</p> <p>In addition to the receipt of the two delayed payments, HBDCA was also delayed by five months in its return to the Royal London Haemophilia Department and also in its commencement of the Kent and Canterbury one year pilot. This reduced anticipated funding from these two major sources. However, HBDCA has nevertheless managed to remain solvent with funds in the positive whilst increasing the services it provides to a greater number of people.</p> <p>N.B. HBDCA has carried out a financial forecast showing that it should be in a position to hold two months' reserves in the coming financial year, 2022 – 2023, and potentially up to one year's reserves, in the following financial year, 2023 - 2024.</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 therapists of the highest calibre and by HBDCA's reputation continuing to grow within the bleeding disorder arena, 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 committed to provide. We have increased the psychotherapeutic team by one and will address this issue further in 2023.</p>
In conclusion	<p>HBDCA has, despite issues such as the delayed return to the Royal London Hospital Haemophilia Department and the delayed commencement of services at the Kent and Canterbury Haemophilia Department, continued to grow and to thrive.</p> <p>As well as client/patient numbers increasing this year, in all areas of HBDCA activity, HBDCA has also increased its team numbers and put in place new strands of support for the team itself as well as ensuring HBDCA governance documents and policies are fit for purpose.</p> <p>HBDCA has benefitted from the election of a new trustee in November, 2021, Cynthia Creavalle, with her particular expertise in financial management as well as her experience in already having worked in the bleeding disorder community. HBDCA is also soon to engage a new book-keeper.</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>

Structure, Governance and Management

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

The charity's organisational structure and any wider network with which the charity works	<p>HBDCA is led by four trustees: the Chair, Nina Beer, along with Joseph Peaty, Jacqueline Brooks and Cynthia Creavalle. HBDCA also has an ambassador, Ros Cooper.</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 six-fold therapeutic team and by the bleeding disorder community itself.</p> <p>HBDCA works closely with the Haemophilia Department at the Royal London Hospital to provide psychological support to their patients, including family members.</p> <p>It 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 the England Infected Blood Support Scheme (EIBSS).</p>
Relationship with any related parties	<p>HBDCA is now an approved provider of psychological support for the Royal London Haemophilia Department, the Terrence Higgins Trust Counselling Service and EIBSS. It collaborates with the charity, Local Families with Bleeding Disorders, The UK Haemophilia Society and with the Hepatitis C Trust.</p>

Other	<p>HBDCa also has a burgeoning relationship with Haemnet which carries out research within the bleeding disorder community. This relationship has enabled HBDCa to provide valuable insight through the review of academic papers on the psychological impact of bleeding disorders. It has also enabled HBDCa to learn from some of the research carried out. For instance, on gene therapy, and what might be some of the psychological issues to be considered for this new treatment which is currently being trialled.</p> <p>This collaborative approach will enable HBDCa not only, potentially, to contribute to improved quality of life for people across the UK with a bleeding disorder but will also enable the HBDCa team to continue to learn, and, therefore, maintain, up-to-date knowledge of the ever-changing, fast-moving landscape of medical care this community is currently experiencing. And will enable HBDCa to be at the forefront of psychological and psychosocial provision for people with bleeding disorders.</p>
Future Plans	<p>HBDCa aims to consolidate and strengthen its provision of psychological support at the Royal London Hospital Haemophilia Department.</p> <p>It will replicate this model of psychological provision in the coming year, with a further Haemophilia Centre (outside London) with whom it has nearly concluded contractual matters.</p> <p>HBDCa also anticipates carrying out a pilot event for one further London Haemophilia Centre in the coming year as a trial which will potentially lead to further work with this Centre in support of its patients.</p> <p>HBDCa will continue to support the Infected Blood community, particularly in anticipation of the conclusion of the Infected Blood Inquiry (expected later in 2022 or early in 2023) and the psychological impact this may have on the Infected Blood community.</p> <p>HBDCa will continue to develop the relationships it has with liked-minded organisations, with the intention of collaborating on wellbeing events which will</p>

	<p>benefit the bleeding disorder community across the UK, as well as through the sharing of knowledge and expertise with these organisations and their members.</p> <p>HBDCa will also continue to support its therapy team and trustees in the coming year through the provision of a training day and will also provide the therapy team with further learning opportunities, including access to specialised training provided by the Royal London Hospital.</p>
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Exemptions from disclosure


Reason for non-disclosure of key personnel details

N/A

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)	Joseph Paul Peaty	
Position (e.g., Secretary, Chair, etc)	Trustee	
Date	30/01/2023	

Independent Examiner's Report to the Trustees For the year ended 31 March 2022

I report to the Trustees on my examination of the accounts of the charitable company for the year ended 31 March 2022.

Responsibilities and basis of report

The charity Trustees, who are also Directors for the purposes of company law, are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiners statement

I have completed my examination. I confirm that no 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 Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the requirements of section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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 to enable a proper understanding of the accounts to be reached.

Approved on 30th January 2023

Haroon Ashfaq ACCA

Statement of Financial Activities (including summary of Income and Expenditure Account)
Year ended 31 March 2022

	Note	Unrestricted Funds £	Restricted Funds £	2022 Total Funds £	Unrestricted Funds £	Restricted Funds £	2021 Total Funds £
<u>Income and Charitable Activities</u>							
Grants & Donations	3	56,737	0	56,737	23,544	1,500	25,044
<u>Expenditure on:</u>							
Raising funds	4	29,078	0	29,078	21,193	350	21,543
Charitable activities	4	13,519	0	13,519	1,452	0	1,452
Other	4	615	0	615	151	0	151
		43,212	0	43,212	22,796	350	23,146
Net (Expenditure)/Income		13,525	0	13,525	748	1150	1,898
<u>Reconciliation of funds:</u>							
Total funds brought forward		748	1,150	1,898	0	0	0
Total funds carried forward	3	14,273	1,150	15,423	748	1,150	1,898

Balance Sheet
As at 31 March 2022

	Note	March 2022	March 2021
Cash at bank and in hand		742	1,898
Trade Debtors		<u>24,112</u>	<u>0</u>
		24,854	1,898
Creditors: amounts falling due within one year	5	(9,431)	(0)
Total Net Assets		<u><u>15,423</u></u>	<u><u>1,898</u></u>
Restricted Income Funds	3	1,150	1,150
Unrestricted Funds	3	<u>14,273</u>	<u>748</u>
		<u><u>15,423</u></u>	<u><u>1,898</u></u>

The charity was entitled to exemption from audit under s477 of the Companies Act 2006 relating to small entities.

The members have not required the charity to obtain an audit in accordance with section 476 of the Companies Act 2006.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act with respect to accounting records and the preparation of accounts.

These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime and in accordance with FRS102 SORP.

The accounts were approved by the Trustees on 28th January 2023 and signed on their behalf by: -

Joseph Paul Peaty



Trustee

Notes to the financial statements

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 16 July 2014 (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.

3 Movement in Funds

	At the Start of the Year £	Incoming Resources £	Outgoing Resources £	At the End of the Year £
Restricted Funds	1,150	0	0	1,150
Unrestricted Funds	748	56,737	43,212	14,273
Total Funds	1,898	56,737	43,212	15,423

4 Expenditure

	Unrestricted	Restricted	2022 Total £	Unrestricted	Restricted	2021 Total £
<u>Expenditure on raising funds:</u>						
Staff & CEO Fee	21,228	0	21,228	21,193	350	21,543
Management fee	7,850		7,850			
	29,078	0	29,078	21,193	350	21,543
<u>Expenditure on Charitable activities:</u>						
Advertising & Marketing	4,875	0	4,875	0	0	0
Audit & Accountancy fees	1,650	0	1,650	0	0	0
Bank Fees	168	0	168	0	0	0
Telephone & Internet	0	0	0	1,198	0	1,198
Legal & Professional	0	0	0	110	0	110
IT & Software	2,263	0	2,263	144	0	144
Travel & Subsistence	4,563	0	4,563	0	0	0
	13,519	0	13,519	1,452	0	1,452
<u>Other</u>						
Sundry expenses	615	0	615	151	0	151
	615	0	615	151	0	151
Total	43,212	0	43,212	22,796	350	23,146

	March 2022 £	March 2021 £
5 Creditors: amounts falling due with in one yaer		
Trade Creditors	3,728	0
Other Creditots	5,703	0
	9,431	0

The charity has no employees and, therefore, no employee earning more than £30,000 per annum. Staff fees above consist of payments to freelancers.

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

HBDCA

England & Wales - Charity number 1191416

Accounts



HBDCA

Annual Report and Financial Statements

Year ended 31st March 2021

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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>

HBDCA Organisational Structure

Trustees

Nina Beer

Governance and Fundraising

Joseph Peaty

Patient expert: Inhibitors and Infected Blood

Jackie Brooks

Finance and carers

Ambassador - Ros Cooper

Specialism: Women 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

Joined HBDCA early 2021

Jon Stringer

Adult Peer Mentor/Patient Advocate

Joined HBDCA early 2021

Name of chief executive or names of senior staff members

Christina Burgess

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	Jacqueline Brooks			
4				
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6				
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HBDCA Trustees' Annual Report

For the period: 1 April 2020 to 31 March 2021

Charity name: HBDCA
(Haemophilia and Bleeding Disorders Counselling Association)

Charity registration number: 1191416

Objectives and Activities

<p>Summary of the purposes of the charity as set out in its governing document</p>	<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>
<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>	<p>The Royal London Hospital Haemophilia Department</p> <p>Despite the success of the 6-month pilot which ended in December 2019, HBDCA was not then able to return to the Royal London Hospital Haemophilia Department in early 2020, as had been anticipated, due to the Covid-19 pandemic.</p> <p>However, HBDCA maintained close contact with the department throughout the period April 1, 2020 – 31 March, 2021. Due to the major impact of the Covid-19 pandemic, HBDCA offered staff, and patients alike, crisis support should they require it during this time.</p> <p>The main activity carried out between HBDCA and the RLH in January 2021 was the commencement, at the Royal London's request, of negotiations for an anticipated</p>

	<p>return by HBDCA in April 2021 to provide psychological support to its patients on a long-term, permanent basis.</p> <p>This support will consist of one-to-one psychological counselling, quarterly, themed wellbeing workshops, and the facilitation of peer support groups for adults with a bleeding disorder and facilitation of a peer support group for parents of newly diagnosed children. A peer support group for women with bleeding disorders will also be facilitated by HBDCA.</p> <p>One patient at the RLH, who was identified by the RLH as being in urgent need of psychological support, has been provided with therapy by HBDCA since March, 2021, in anticipation of HBDCA's imminent return.</p> <p>The Terrence Higgins Trust/Macfarlane Trust Counselling Service</p> <p>In early 2020, campaigners from the Infected Blood community recommended to the Terrence Higgins Trust/MacFarlane Trust, (THT), who were considering setting up a counselling service using monies assigned to the Terrence Higgins Trust from the closed-down MacFarlane Trust, that HBDCA should be involved in this new service. In April, 2020, HBDCA was invited by THT to advise on the setting up of processes and the creation of a robust client pathway. This work was duly completed and in early July, 2020, HBDCA became the only named psychological support charity on the THT list of approved therapists and psychological support organisations. N.B. 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>HBDCA commenced the provision of psychological support to THT clients at the end of July, 2020. HBDCA initially supported 2 clients with this number having increased to 8 clients by March, 2021. For these 8 clients, HBDCA carried out 120 psychological support sessions between July 25, 2020 and March, 31, 2021.</p> <p>EIBSS (England Infected Blood Support Scheme)</p>
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	<p>From December 2020 – March 2021 HBDCA carried out 20 psychological therapy sessions for two clients.</p> <p>As well as providing psychological therapy, HBDCA was also required to write letters on behalf of each client to EIBSS in support of their therapy and why it was needed in order for the clients to be awarded funding by EIBSS.</p> <p>Needlephobia Workshop for Local Families with Bleeding Disorders (LFwBD) charity</p> <p>HBDCA realised, following a virtual meeting in early 2021 with the charity, LFwBD, of which Christina Burgess is a committee member and volunteer, that needle-phobia is a major issue for many parents and children, especially due to new treatment regimes which require subcutaneous injections of children. Funding for a needle-phobia workshop was therefore sought. The pharmaceutical company, Chugai UK/Roche, awarded an educational grant of £1500 to HBDCA on 26 March, 2021 to carry out a virtual needle-phobia workshop. The needle-phobia workshop took place in May, 2021. An account of the needle-phobia workshop will be provided in the next year's annual return and report (2021 – 2022).</p> <p>Infected Blood Inquiry and community</p> <p>Due to the pandemic, it was not possible to attend the Public Inquiry in person during April 2020 – March, 2021, but HBDCA continued to monitor closely the hearings and their outcomes in order to understand better the impact they might have on the Infected Blood community, some of whose members it supports psychologically.</p> <p>HBDCA has been exploring, since 2021, the possibility of having an MoU with two other charities which work with this community: The UK Haemophilia Society and the HepC Trust. These two organisations acknowledge the immense psychological impact the Infected Blood community has experienced (sustained over a 30-year period) and recognise the work HBDCA has been doing in</p>
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	<p>psychological provision for this vulnerable cohort.</p> <p>Providing information for healthcare professionals</p> <p>Podcast: <i>'Understanding the Psychological Impact of Bleeding Disorders on Women'</i></p> <p>In February, 2021, two members of the HBDCA team, Christina Burgess (CB) and Lisa Fowler (LF), were invited to be guest speakers on a podcast produced by the Bleeding Disorders Academy (on behalf of pharmaceutical company, CSL Behring) and developed for UK healthcare professionals. The podcast was due for launch later in 2021.</p> <p>The aim of the podcast was to further educate healthcare professionals, in particular nurses, on this subject, and to provide them with additional insight, from a psychological perspective, on how women and girls with a bleeding disorder are impacted. CB and LF discussed specifically the psychological challenges women and girls can face and the positive impact psychological support can have on them.</p> <p>EAHAD</p> <p>Christina Burgess, who is Secretary of the European Association for Haemophilia and Allied Disorders (EAHAD) Psychosocial Working Group, produced and co-presented a session at the Allied Health Professionals' Day at the EAHAD Annual Congress in February, 2021. The subject was: <i>'The Impact of Covid-19 on healthcare professionals and patients alike'</i>.</p> <p>The premise behind the presentation, which originated from a small study carried out in 2020 by Christina Burgess and her colleague, Petra Buckhova, from the Czech Republic, was to inform psychosocial professionals across Europe, as well as Haemophilia Centres, of important lessons learnt about the psychological impact on both cohorts during Covid-19. And, also, to explore how psychosocial provision might</p>
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	<p>be improved and accessed more easily by patients in any future pandemics. All members of the HBDCA team attended this virtual event.</p> <p>An abstract entitled, '<i>The impact of Covid-19 on healthcare professionals and patients</i>', authored by Petra Buckhova and Christina Burgess was published in the academic journal, Haemophilia, in 2021.</p> <p>Covid-19 psychological support for patients and healthcare professionals in a time of crisis</p> <p>In 2020, as the Covid-19 pandemic began to majorly impact on people's lives, their livelihoods and, especially, their mental wellbeing, HBDCA decided in March 2020, despite not having funding, that it would offer crisis counselling to anyone who might need it during the pandemic.</p> <p>The HBDCA website was updated to publicise the support being offered along with signposting information to other useful organisations and charities. HBDCA notified the bleeding disorder community, both individuals and organisations, such as the UK Haemophilia Society, the Hepatitis C Trust, the Infected Blood community and the European Haemophilia Consortium (EHC), of this support being offered. HBDCA's crisis support initiative still stands and will continue to be available until the pandemic is no longer a threat.</p> <p>HBDCA website</p> <p>HBDCA has, during this period, kept its website up to date not only to promote HBDCA but also to signpost people to other useful links or organisations, particularly during the pandemic. HBDCA also commissioned some short films in 2020 to be produced for the website which will provide a snapshot of the lives of some of the bleeding disorder community and also share some reflections on Covid-19. They will be available in early 2022.</p>
Statement confirming whether the trustees have had regard to the guidance issued by the Charity	The trustees of HBDCA adhere at all times to the principles and guidance issued by the Charity Commission on public benefit and apply these to all activities carried out by HBDCA.

Commission on public benefit	
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Achievements and Performance

<p>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>	<p>The Royal London Hospital Haemophilia Department</p> <p>To continue to develop a strong relationship with the Royal London Haemophilia Department and its patients despite not being able to return to work with them due to the Covid-19 pandemic.</p> <p>And for the commencement in early 2021 of negotiations for a return aimed at April, 2021. This is, in itself, an achievement during such a difficult period, with the RLH actively requesting HBDCA's return as soon as it was in a position to do so, having recognised the value of HBDCA's work in support of their patients during the 2019 pilot.</p> <p>Quote from RLH regarding a patient being supported by HBDCA since March 2021:</p> <p><i>'The patient was, in particular, very, very grateful for your team's intervention and ongoing support which happened at a very challenging time for them. They could not have spoken more highly of what they called 'feeling privileged to receive such excellent care'.</i></p> <p>The Terrence Higgins Trust/Macfarlane Trust Counselling Service</p> <p>To be recommended by the Infected Blood community to be a key contributor to this new counselling service not only in providing psychological support but in the setting up of the service itself. The psychological support provided by HBDCA, since the inception of this new service in July, 2020, will have enabled its beneficiaries to avail themselves, some for the first time in 30 years, of high-quality, effective psychological support provided by therapists at HBDCA with their deep insight into bleeding disorders and into the Infected Blood community. HBDCA believes that its unique understanding of this community has provided those it has</p>
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	<p>supported with much-needed, long-awaited, effective psychological support.</p> <p>Quote from a member of the Infected Blood community: <i>'HBDCA has helped my daughter tremendously with the counselling you have provided her. She is like a different person and everyone can see the change in her thanks to your help. She really was in a bad place before she started counselling and has gained both confidence and strength as well as being able to deal with her anxiety. So, as a father who always felt guilt (because of my HIV diagnosis and how it affected her), I will be eternally grateful for the help you gave, and this makes me feel better.'</i></p> <p>EIBSS</p> <p>Since providing psychological provision through EIBSS, HBDCA has enabled clients access to insightful, high-quality support not previously available to them.</p> <p>Quote from an EIBSS client: <i>'Clare was a great help and now I understand a lot of what I have been enduring over the years and can apply the techniques we discussed. Over the weeks we talked, I came to trust her completely; a very necessary component I believe. It was so marvellous to talk to someone who understood exactly what I, my son and my family, have gone through and which still haunts us all these years later. The service which you and your team offer is absolutely vital. I will never forget the understanding, empathy and encouragement shown by Christina and Clare. It's important to know that I will be able to come to HBDCA for support should things ever become difficult again in the future.'</i></p> <p>Education and Information</p> <p>Through effective communication, by developing relationships with like-minded organisations and healthcare colleagues, and, also, importantly, by listening to the community itself, HBDCA has been able, despite the immense strictures of the pandemic in 2020 - 2021, to reach out to, and inform, not only those infected and affected by a bleeding disorder but also the</p>
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	<p>wider community, about the psychological impact and issues people with bleeding disorders and their family members experience.</p> <p>HBDCa has been able to share coping strategies and tools with those it supports and also with the wider community it works with, including healthcare professionals who might not have previously understood or had any great knowledge of the psychological impact a bleeding disorder can have on members of this unique community.</p> <p>Covid-19 psychological support for patients and healthcare professionals in a time of crisis</p> <p>HBDCa is proud to have played a small part during the Covid-19 pandemic by supporting clients, patients and healthcare professionals themselves on an ongoing basis by offering crisis support to anyone who might need it.</p> <p>In addition, through the EAHAD study carried out by Christina Burgess, HBDCa hopes to potentially inform how psychological support might be better provided and accessed by patients, through their Haemophilia Centres, for future pandemics. And, also, how psychosocial professionals forming an integral part of any Centre's multidisciplinary team (MDT), as a part of holistic support, should become standard.</p> <p>Without fail, throughout the pandemic, HBDCa has held a weekly Zoom meeting with its therapy team, and regular Zoom meetings with the Trustees, the main purpose being to ensure members of HBDCa felt supported and less isolated. This has been an important part of the HBDCa culture which believes that supporting one's team and colleagues ensures improved support for clients and patients.</p> <p>Charitable Incorporated Organisation</p> <p>HBDCa is very proud to have been awarded CIO status in September, 2020, and views this as a very important achievement.</p>
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HBDC A Strategic Plan 2020 - 2021

<p>HBDC A will provide effective, high-quality, tailored psychosocial support to patients, their family members and carers at The Royal London Hospital Haemophilia Centre</p> <p>HBDC A will support members of the Infected Blood community across the United Kingdom</p> <p>HBDC A will provide psychosocial support to one further London Centre and its patients, family members and carers</p>
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<p>Achievements against objectives set in Strategic Plan 2020 - 2021</p>	<p>HBDC A, during a challenging, unprecedented year, caused by the Covid-19 pandemic, was unable to fulfil properly the first part of its strategic plan for 2020 – 2021. Nevertheless, it continued, with all the means it had available, to develop the relationship with the Royal London throughout this period, to the extent that HBDC A was then invited by the Royal London Hospital Haemophilia Centre as soon as it was in a position to do so, to ask HBDC A to return to work with their patients on a long-term, permanent basis to commence in April, 2021.</p>
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	<p>HBDCA supported members of the Infected Blood community across the United Kingdom very effectively through its work with the THT/MacFarlane Trust counselling service and through EIBSS. HBDCA has also demonstrated support for this community through actively engaging with like-minded charities such as the UK Haemophilia Society and the Hepatitis C Trust, and by keeping up to date and informed with all the outcomes of the Inquiry.</p> <p>Although HBDCA, during this period, did not support a further London Haemophilia Centre, it commenced conversations with one further London centre, which are ongoing, as well as commencing, and nearly having concluded, negotiations with a Haemophilia Department outside London.</p>
Investment performance against objectives	All the objectives achieved during the period 1 April 2020 – 31 March 2021, despite a challenging financial climate due to Covid-19, were carried out within the monies received by HBDCA.

Financial Review

Review of the charity's financial position at the end of the period	In brief, despite the most challenging period in recent history, HBDCA ended the period with £1897.69, fulfilling many activities throughout the 12 months. The details of the financial position and activity is contained within the Financial Return for HBDCA for April 1, 2020 – 31 March, 2021.
Statement explaining the policy for holding reserves stating why they are held	It is HBDCA's policy to hold reserves in order to safeguard the long-term future and sustainability of the CIO. The security reserves offer will provide HBDCA with the ability to maintain, continue to provide, and also, to increase, the provision of specialised, psychological support to the bleeding disorder community.
Amount of reserves held	Restricted = £1,150 Unrestricted = £748
Reasons for holding zero reserves	<p>At the start of 2020, just as HBDCA was due to resume its support of patients at the Royal London Haemophilia Department, the world was hit by the Covid-19 coronavirus pandemic. HBDCA's return, out of necessity, by the hospital, was put on hold. Anticipated funding from this particular source, therefore, did not materialise. Despite this major reduction in income due to the pandemic HBDCA has nevertheless managed to remain solvent with funds in the positive..</p> <p>HBDCA aims, during the new financial year, with an anticipated return date for April, 2021 to the Royal London Haemophilia Department, to hold 6 months' reserves, and, ideally, 1 year's reserves, in the coming financial year.</p>

Additional information

A description of the principal risks facing the charity	<p>The principal risk for HBDCA would be through lack of funding for the provision of psychological care. Through keeping costs and overheads to a minimum, by only working with therapists of the highest calibre and by HBDCA's reputation continuing to grow within the bleeding disorder arena, 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>
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	<p>committed to provide but this year HBDCA has increased its therapy team by one, as well as also welcoming an adult peer mentor. HBDCA will continue to increase its team numbers but this is a process it carries out with a cautious, measured approach, as it wants to ensure that the therapists engaged are of the right calibre and will be as passionate, insightful and committed as advocates for this community as the current HBDCA therapy team are.</p>
Covid-19	<p>The Covid-19 pandemic has thrown a vast spotlight on mental health!</p> <p>HBDCA has, despite the numerous challenges of the last year, including the lack of anticipated funding, continued not only to grow but to thrive, and, crucially, to offer a safe, welcoming environment to all those it has supported during the period of this report. Often, not only counselling them with regard to their bleeding disorder but, at the same time, providing them with a much-needed element of psychological support during the pandemic.</p>

Structure, Governance and Management

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

The charity's organisational structure and any wider network with which the charity works	<p>HBDCA is led by three trustees: the Chair, Nina Beer, along with Joseph Peaty and Jacqueline Brooks. HBDCA also has an ambassador, Ros Cooper.</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 five-fold therapeutic team, the adult peer-mentor, and by the bleeding disorder community itself.</p> <p>HBDCA works closely with the Haemophilia Department at the Royal London Hospital to provide psychological support to their patients, including family members.</p> <p>It 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 EIBSS (England Infected Blood Support Scheme).</p>
Relationship with any related parties	<p>HBDCA is now an approved provider of psychological support for the Royal London Haemophilia Department, the Terrence Higgins Trust Counselling Service and EIBSS. It collaborates with the charity, Local Families with Bleeding Disorders, The UK Haemophilia Society and with the Hepatitis C Trust.</p>

Other	<p>HBDCa also has a burgeoning relationship with Haemnet which carries out research within the bleeding disorder community. This relationship has enabled HBDCa to provide valuable insight through the review of academic papers on the psychological impact of bleeding disorders. It has also enabled HBDCa to learn from some of the research carried out. For instance, on gene therapy, and what might be some of the psychological issues to be considered for this new treatment which is currently being trialled.</p> <p>This collaborative approach will enable HBDCa not only, potentially, to contribute to improved quality of life for people across the UK with a bleeding disorder but will also enable the HBDCa team to continue to learn, and, therefore, maintain, up-to-date knowledge of the ever-changing, fast-moving landscape of medical care this community is currently experiencing. And will enable HBDCa to be at the forefront of psychological and psychosocial provision for people with bleeding disorders.</p>
Future Plans	<p>HBDCa aims to consolidate and strengthen its provision of psychological support at the Royal London Hospital Haemophilia Department.</p> <p>It will replicate this model of psychological provision in the coming year, with a further Haemophilia Centre (outside London) with whom it has nearly concluded contractual matters.</p> <p>HBDCa also anticipates carrying out a pilot event for one further London Haemophilia Centre in the coming year as a trial which will potentially lead to further work with this Centre in support of its patients.</p> <p>HBDCa will continue to support the Infected Blood community, particularly in anticipation of the conclusion of the Infected Blood Inquiry (expected later in 2022 or early in 2023) and the psychological impact this may have on the Infected Blood community.</p> <p>HBDCa will continue to develop the relationships it has with liked-minded organisations, with the intention of</p>

	<p>collaborating on wellbeing events which will benefit the bleeding disorder community across the UK, as well as through the sharing of knowledge and expertise with these organisations and their members.</p> <p>HBDCa will also continue to support its therapy team and trustees in the coming year through the provision of a training day and will also provide the therapy team with further learning opportunities, including access to specialised training provided by the Royal London Hospital.</p>
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Exemptions from disclosure

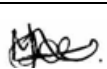
Reason for non-disclosure of key personnel details

N/A

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)	Nina Janine Beer	
Position (e.g., Secretary, Chair, etc)	Chair	
Date	28/01/2022	

Independent Examiner's Report to the Trustees For the year ended 31 March 2021

I report to the Trustees on my examination of the accounts of the charitable company for the year ended 31 March 2021.

Responsibilities and basis of report

The charity Trustees, who are also Directors for the purposes of company law, are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiners statement

I have completed my examination. I confirm that no 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 Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the requirements of section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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 to enable a proper understanding of the accounts to be reached.

Approved on 28th January 2022

Haroon Ashfaq ACCA

Statement of Financial Activities (including summary of Income and Expenditure Account)
Year ended 31 March 2021

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds £
Income and Charitable Activities				
Grants & Donations	3	<u>23,544</u>	<u>1,500</u>	<u>25,044</u>
Expenditure on;				
Raising funds	4	21,193	350	21,543
Charitable activities	4	1,452	0	1,452
Other	4	151	0	151
		<u>22,796</u>	<u>350</u>	<u>23,146</u>
Net (Expenditure)/Income		748	1150	1,898
Reconciliation of funds;				
Total funds brought forward		0	0	0
Total funds carried forward	3	<u><u>748</u></u>	<u><u>1,150</u></u>	<u><u>1,898</u></u>

Balance Sheet
As at 31 March 2021

	Note	
Cash at bank and in hand		1,898
Total Net Assets		<u>1,898</u>
Restricted Income Funds	3	1,150
Unrestricted Funds	3	<u>748</u>
		<u>1,898</u>

The charity was entitled to exemption from audit under s477 of the Companies Act 2006 relating to small entities.

The members have not required the charity to obtain an audit in accordance with section 476 of the Companies Act 2006.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act with respect to accounting records and the preparation of accounts.

These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime and in accordance with FRS102 SORP.

The accounts were approved by the Trustees on 28th January 2022 and signed on their behalf by: -

Nina Janine Beer



Chair

Notes to the financial statements

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 16 July 2014 (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.

3 Movement in Funds

	At the Start of the Year £	Incoming Resources £	Outgoing Resources £	At the End of the Year £
Restricted Funds	0	1,500	-350	1,150
Unrestricted Funds	0	23,544	-22,796	748
Total Funds	0	25,044	-23,146	1,898

4 Expenditure

	Unrestricted	Restricted	Total £
Expenditure on raising funds;			
Staff & CEO Fee	21,193	350	21,543
	<u>21,193</u>	<u>350</u>	<u>21,543</u>
Expenditure on Charitable activities;			
Telephone & Internet	1,198		1,198
Legal & Professional	110		110
IT & Software	144		144
	<u>1,452</u>	<u>0</u>	<u>1,452</u>
Other			
Sundry expenses	£151.00		151
	<u>151</u>	<u>0</u>	<u>151</u>
Total	<u>22,796</u>	<u>350</u>	<u>23,146</u>

The charity has no employees and, therefore, no employee earning more than £30,000 per annum. Staff fees above consist of payments to freelancers.

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

No trustee expenses have been incurred.