

HBDCA

Annual Report and Financial Statements

Year ended 31st March 2024

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

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>
Relationship with any related parties	<p>HBDCA is an approved provider of psychological support for the Royal London Haemophilia Department, the Kent and Canterbury Haemophilia Department, 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>
Other	<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>

HBDCa Trustees' Annual Report

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

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

Charity registration number: 1191416

Objectives and Activities

Summary of the purposes of the charity as set out in its governing document	<p>To promote and protect the physical and mental health of people in the UK affected by a bleeding disorder, their families and carers through:</p> <p>A) The provision of counselling and therapy;</p> <p>B) Providing workshops, support and signposting.</p> <p>C) Raising awareness of the need for support for people affected by a bleeding disorder.</p> <p>D) Providing workshops to professionals to provide insight and to improve the support they provide to the bleeding disorder community.</p>
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	<p>The Royal London Hospital Haemophilia Department (RLH)</p> <p>Throughout this period, HBDCa continued to support patients and family members at the Royal London Hospital Haemophilia Department (RLH). 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 HBDCa 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 HBDCa runs on a voluntary basis. There are now 11 members of this group from across the UK.</p>

	<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.</p> <p>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.</p> <p>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.</p> <p>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.</p> <p>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.</p> <p>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.</p> <p>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.</p> <p>Continuing and new themes identified during psychotherapy sessions:</p> <ul style="list-style-type: none"> • Impact on women who have experienced issues when contemplating starting a family, whether this be infertility, miscarriage or judgement from relatives and family members. • A heightened sense of isolation for women in the ultra-rare cohort is a common experience. Another common story is of difficulty getting diagnosed.
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	<ul style="list-style-type: none"> • 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. <p>The Kent and Canterbury Hospital Haemophilia Department (K&C)</p> <p>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.</p> <p>This provision affords a similar level of psychological support to K&C patients to that provided to patients at the Royal London.</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 workshop.</p> <p>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.</p> <p>Two patients at the K&C continue to be members of the Rare Peer Support Group.</p>
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	<p>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.</p> <p>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.</p> <p>Statement from HBDCa Child Psychologist about her work with HBDCa including with children and young people from the K&C:</p> <p><i>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</i></p> <p>Oxford University Hospital Haemophilia Centre</p> <p>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.</p> <p>HBDCa will participate in the Oxford Centre's 5-year Peer Review in May, 2024.</p> <p>The London Clinic</p> <p>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.</p> <p>University Hospital Southampton Haemophilia Centre</p> <p>It is anticipated that HBDCa will commence support for patients and family members at UHS in the coming year.</p>
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	<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 120 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 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).</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 fully in late 2024.</p> <p>Birmingham Hospital Haemophilia Department - Haematology - University Hospitals Birmingham NHS Foundation Trust</p> <p>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.</p> <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 11 members ranging in ages from early twenties to mid-seventies, including the mother of a young child with Glanzmann's Thrombasthenia.</p> <p>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.</p> <p>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</p>
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	<p>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>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</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 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.</p> <p>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.</p> <p>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.</p> <p>40 meetings were held between 1 April 2023 to 31 March, 2024.</p> <p>Statement from a member of the ‘affected’ community:</p> <p><i>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.</i></p>
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	<p><i>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></p> <p><i>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.</i></p> <p><i>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.</i></p> <p><i>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.</i></p> <p><i>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.</i></p> <p><i>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></p> <p><i>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</i></p> <p>England Infected Blood Support Scheme (EIBSS)</p> <p>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.</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>
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	<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 fourth 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 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.</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, Haemosexual and the Hepatitis C Trust.</p> <p>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.</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, 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.</p> <p>Quote from a member of the Infected Blood community:</p> <p><i>I write to express my thanks for what has been overwhelming support with HBDCA providing such vitally important services.</i></p>
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	<p><i>I have received the most courteous and considerate care from you all. Anonymous</i></p> <p>Statement from a key campaigner and member of the Infected Blood community:</p> <p><i>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 case 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</i></p> <p>HBDCa Team-building Day, September 2023</p> <p>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.</p> <p>Statements from members of the HBDCa psychotherapeutic team on what their work and HBDCa means to them:</p> <p><i>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</i></p>
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	<p><i>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.</i></p> <p><i>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></p> <p><i>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></p> <p><i>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</i></p> <p><i>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</i></p> <p>Trustees</p> <p>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.</p> <p>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.</p> <p>Trustees' Meetings</p> <p>Trustees' meetings took place on:</p> <p>27 April, 2023 19 July, 2023 17 September, 2023 18 October, 2023 (AGM)</p>
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13 December, 2023
22 March, 2024

HBDCa Psychology in Gene Therapy European Roundtable

Following on from the success of the 2023 UK roundtable conceived, organised and managed by HBDCa, 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.

HBDCa website

Having had this work delayed due to the unavailability of the website professional tasked with carrying out this work, HBDCa 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.

HBDCa 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 HBDCa's voluntary work and recognise further the team and the value they bring to HBDCa.

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. HBDCa 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>
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

<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 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, HBDCA's 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>HBDCA 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. HBDCA 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 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</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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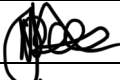
Structure, Governance and Management

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.

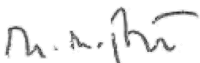
Independent examiners statement

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> 52,769	<u>1,578</u> 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> 19,357	<u>(601)</u> 10,795

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

		Computer equipment £
3	Tangible fixed assets	
	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
	Other debtors	9,018
		<u>16,780</u>
		<u>28,673</u>
5	Creditors:	March 2024
		March 2023
	Amounts falling due with in one year	
	Trade Creditors	-
	VAT	9,853
	Accruals	990
	Deferred Income	21,167
	Other creditors	1,934
		<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

Expenditure on Charitable activities:

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

Other

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