



# **HBDCA**

## **Annual Report and Financial Statements**

**Year ended 31<sup>st</sup> March 2022**

**Charity Number: 1191416**

## Contents

	Page
Administrative details	3
Trustees' Report	7
Independent Examiner's Report	26
Statement of Financial Activities	27
Balance Sheet	28
Notes to the Financial Statements	29

## 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 2022</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

**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				

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

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.

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.

HBDCA works closely with the Haemophilia Department at the Royal London Hospital to provide psychological support to their patients, including family members.

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).

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

Summary of the purposes of the charity as set out in its governing document	<p><b>To promote and protect the physical and mental health of people in the UK affected by a bleeding disorder, their families and carers through:</b></p> <p><b>A) The provision of counselling and therapy;</b></p> <p><b>B) Providing workshops, support and signposting.</b></p> <p><b>C) Raising awareness of the need for support for people affected by a bleeding disorder.</b></p> <p><b>D) Providing workshops to professionals to provide insight and improve the support they provide to the bleeding disorder community.</b></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><b>The Royal London Hospital Haemophilia Department (RLH)</b></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"> <li>• Women with Bleeding Disorders</li> <li>• Empowerment and Pain Management</li> <li>• Gene Therapy.</li> </ul>
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	<p><b>Some themes identified during psychotherapy sessions:</b></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><b>The Kent and Canterbury Hospital Haemophilia Department (K&amp;C)</b></p> <p>In September, 2021, HBDCA commenced contractual talks with the K&amp;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&amp;C, HBDCA provided psychotherapeutic support in late 2021 and early 2022 to three patients from the K&amp;C who had been identified as being in urgent need of psychological support.</p> <p><b>St George's Hospital Haemophilia Department</b></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><b>University Hospital Southampton Haemophilia Department (UHS)</b></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><b>The Terrence Higgins Trust/Macfarlane Trust Counselling Service (THT)</b></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><b>England Infected Blood Support Scheme (EIBSS)</b></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><b>Needlephobia Workshop for Local Families with Bleeding Disorders (LFwBD) charity</b></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><b>Infected Blood Inquiry and community</b></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><b>Providing information for healthcare professionals</b></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><b>European Association for Haemophilia and Allied Disorders (EAHAD)</b></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><b>European Haemophilia Consortium (EHC)</b></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><b>HBDCA website</b></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><b>HBDCA Governance and Team Support</b></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><b>The Royal London Hospital Haemophilia Department</b></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><b>Comment from a senior member of the MDT at the RLH:</b></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><b>The Terrence Higgins Trust/Macfarlane Trust Counselling Service (THT)</b></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><b>England Infected Blood Support Scheme (EIBSS)</b></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><b>Below is a quote from one of the clients HBDCA supports in the Infected Blood community:</b></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><b>Education and Information</b></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><b>Covid-19 psychological impact on healthcare professionals and patients</b></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**

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

Achievements against objectives set in Strategic Plan 2020 - 2021	<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	<p>All the objectives achieved during the period 1 April 2021 – 31 March 2022, were carried out within the monies received by HBDCA.</p>

## Financial Review

Review of the charity's financial position at the end of the period	<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>
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, the specialised psychological support it offers the bleeding disorder community.
Amount of reserves held	None.
Reasons for holding zero reserves	<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	<b>Constitution</b>
How is the charity constituted?	<b>Charitable Incorporated Organisation</b>
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	<b>Election to post</b>

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 like-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

<b>Signature(s)</b>		
<b>Full name(s)</b>	Joseph Paul Peaty	
<b>Position (e.g., Secretary, Chair, etc)</b>	Trustee	
<b>Date</b>	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 30<sup>th</sup> 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	<b>56,737</b>	23,544	1,500	<b>25,044</b>
<u>Expenditure on:</u>							
Raising funds	4	29,078	0	<b>29,078</b>	21,193	350	<b>21,543</b>
Charitable activities	4	13,519	0	<b>13,519</b>	1,452	0	<b>1,452</b>
Other	4	615	0	<b>615</b>	151	0	<b>151</b>
		43,212	0	<b>43,212</b>	22,796	350	<b>23,146</b>
Net (Expenditure)/Income		13,525	0	<b>13,525</b>	748	1150	<b>1,898</b>
<u>Reconciliation of funds:</u>							
Total funds brought forward		748	1,150	<b>1,898</b>	0	0	<b>0</b>
Total funds carried forward	3	14,273	1,150	<b>15,423</b>	748	1,150	<b>1,898</b>

**Balance Sheet**  
**As at 31 March 2022**

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

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 28<sup>th</sup> 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
<b>Total Funds</b>	<b>1,898</b>	<b>56,737</b>	<b>43,212</b>	<b>15,423</b>

**4 Expenditure**

	Unrestricted	Restricted	2022 Total £	Unrestricted	Restricted	2021 Total £
<u>Expenditure on raising funds:</u>						
Staff & CEO Fee	21,228	0	<b>21,228</b>	21,193	350	<b>21,543</b>
Management fee	7,850		<b>7,850</b>			
	<b>29,078</b>	<b>0</b>	<b>29,078</b>	<b>21,193</b>	<b>350</b>	<b>21,543</b>

Expenditure on Charitable activities:

Advertising & Marketing	4,875	0	<b>4,875</b>	0	0	<b>0</b>
Audit & Accountancy fees	1,650	0	<b>1,650</b>	0	0	<b>0</b>
Bank Fees	168	0	<b>168</b>	0	0	<b>0</b>
Telephone & Internet	0	0	<b>0</b>	1,198	0	<b>1,198</b>
Legal & Professional	0	0	<b>0</b>	110	0	<b>110</b>
IT & Software	2,263	0	<b>2,263</b>	144	0	<b>144</b>
Travel & Subsistence	4,563	0	<b>4,563</b>	0	0	<b>0</b>
	<b>13,519</b>	<b>0</b>	<b>13,519</b>	<b>1,452</b>	<b>0</b>	<b>1,452</b>

Other

Sundry expenses	615	0	<b>615</b>	151	0	<b>151</b>
	<b>615</b>	<b>0</b>	<b>615</b>	<b>151</b>	<b>0</b>	<b>151</b>
<b>Total</b>	<b>43,212</b>	<b>0</b>	<b>43,212</b>	<b>22,796</b>	<b>350</b>	<b>23,146</b>

**5 Creditors: amounts falling due with in one yaer**

	March 2022 £	March 2021 £
Trade Creditors	3,728	0
Other Creditots	5,703	0
	<b>9,431</b>	<b>0</b>

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.