



Trustees' Annual Report

For the Year from 1 April 2018 to 31 March 2019



The Ben Williams Trust
children with arrhythmia youth cricket initiatives

Section A Reference and administration details

Charity name: The Ben Williams Trust

Registered charity number: 1116627

Charity's principal address: Crofton
Park Road
Haslemere
Surrey GU27 2NL

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	Philip Williams	Chair		
2	Gillian Williams			
3	Paul Grimwood			
4	Deborah Grimwood	Secretary		
5	David Newman			
6	Jonathan Williams			

Names and addresses of advisers

Type of adviser	Name	Address
Solicitor	Hart Brown	Resolution House Riverview Walnut Tree Close Guildford Surrey GU1 4UX
Banker	NatWest	39 The Borough Farnham Surrey GU9 7NP
Independent Examiner	Andy McAllister CA(SA)	54 Stafford Road Petersfield Hampshire GU32 5RB

<p>Summary of the our purposes as set out in our governing document</p>	<p>Ben Williams was a warm hearted, talented and cheerful boy with a love of all sport and a particular passion for cricket. A keen wicketkeeper and batsman, he played for Haslemere Preparatory School, the Royal Grammar School in Guildford and Grayswood CC, and he represented West Surrey and Surrey from the U9 age group onwards. He went on tour with Surrey to Holland in 2000 and Perth, Australia in 2004. Ben was very much a team player, always encouraging others, and he enjoyed coaching and helping those younger than himself.</p> <p>At the age of 14 he was found to have a heart arrhythmia, which resulted in him having to stop all forms of sport and physical activity. He died five months later in February 2006 shortly after collapsing at school. It was subsequently determined that he had a rare heart muscle disorder.</p> <p>The Trust has been set up in Ben’s memory. Its objects are:</p> <ul style="list-style-type: none"> • To relieve sickness and preserve the health of children and young people suffering from heart muscle disorders, for example by: <ul style="list-style-type: none"> – Providing or assisting in the provision of equipment facilities and services not normally provided by the statutory authorities – Sponsoring and helping to develop nursing posts and other mechanisms of support for children and young people with heart disorders and their families – Supporting the development of the Royal Brompton Hospital as an epicentre of excellence and the forging of links with other institutions – Supporting improved pathology for cases of sudden death in children and young people – Raising awareness of heart muscle disorders in children and young people – Supporting research into the diagnosis control and treatment of heart muscle disorders in children and young people – Supporting the development and provision of resource centres for information on heart muscle disorders in children and young people. • To provide or assist in the provision of facilities, equipment and coaching for children and young people to play cricket; <p>Whilst the cricketing related objects of the Trust are broad, the Trustees are most keen to support the development of young wicket-keepers.</p>
<p>Summary of our main activities in relation to those purposes for the public benefit</p>	<p>Children with Arrythmia</p> <p>The Trust has provided seed-corn funding for two ground-breaking new posts on the children’s inherited cardiac condition care team at the Royal Brompton Hospital, London (“the Brompton”); a paediatric cardiac electrophysiology nurse specialist and a paediatric cardiac clinical psychologist. Following proof of concept, both of these roles now have statutory funding.</p> <p>The Trust is currently providing seed-corn funding for a third ground-breaking new post, that of nurse consultant, over a two-year period with effect from July 2019.</p>

<p>Summary of our main activities in relation to those purposes for the public benefit (continued)</p>	<p><i>Paediatric cardiac electrophysiology nurse specialist</i></p> <p>The Trust funded the creation of a new paediatric cardiac electrophysiology nurse specialist post at the Brompton, known as “Ben’s Nurse”. The post allowed children with arrhythmias (abnormally fast or slow heart beats) and their families to benefit from specialist nursing knowledge and skills to help live with the consequences of potentially life-changing or even life-threatening diagnoses. Ben’s Nurse provided support to families across the wide geographic area covered by the hospital, visiting homes and liaising with schools, GPs, and other care workers and interested parties.</p> <p>The number of referrals to the ground-breaking nurse specialist service exceeded all expectations. Increasing numbers of children benefitted from additional support with schooling, which equipped teachers and support staff with vital information about the child’s condition, symptoms to watch for and what to do in the event of an emergency. Most importantly, Ben’s Nurse advocated as normal a life as possible for the child during such visits, so that the child is not seen as any different from their peers. Her intervention prevented children from being excluded from school purely as a result of their conditions.</p> <p>Ben’s Nurse also ran her own SVT clinic in support of her consultant, and became a nurse prescriber, helping to significantly improve the outpatient experience.</p> <p>After being supported by the Trust for three years from April 2008 to March 2011, the post now has statutory funding and is seen as a role model for the development of the Brompton’s cardiac nurse specialist service.</p> <p><i>Paediatric cardiac clinical psychologist</i></p> <p>As a natural extension of the nurse specialist post, the Trust funded the creation of a new clinical psychology post for two years from 1 April 2014 to 31 March 2016. Working as part of a multi-disciplinary team, the role promotes psychological well-being, offers support and help with any psychological problems that may arise either with the child or with their family during the period of investigation and following diagnosis. As with Ben’s Nurse, the aim is to help those impacted to live as normal a life as possible.</p> <p>By way of example, the clinical psychologist lends valuable support to:</p> <ul style="list-style-type: none"> • Children at risk of sudden death • Children having to learn to live with implanted devices such as pacemakers and ICDs • Children who have had a cardiac arrest or who have seen siblings have a cardiac arrest • Families where inherited cardiac disease has been diagnosed, possibly after the death of a family member • Children with learning difficulties who require investigation or procedures • Parents struggling to cope with any such situations <p>The post also included an element of research into how the provision of psychological support can be improved, with proactive rather than reactive intervention.</p>
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	<p>As a result of the value that the post delivered, it now receives statutory funding and is seen as a core component of the Brompton's service provision.</p>
<p>Summary of our main activities in relation to those purposes for the public benefit (continued)</p>	<p><i>Nurse Consultant</i></p> <p>The most recent post, in place from July 2019, is that of Nurse Consultant for the inherited cardiac care team, with the aim of delivering further improvement in patient care and understanding of individuals' conditions.</p> <p>The post holder is an expert in her field, driving excellence through service leadership, direct patient care, research and education, without many of the management responsibilities generally associated with roles of this level of seniority.</p> <p>The Nurse Consultant will devote at least half of her time to clinical work, focusing on acute, long term and more complex cases, and providing expert support and advice to nursing staff in patient care delivery.</p> <p>Equally importantly, she will be using her academic achievement and exceptional knowledge and skills in this highly specialised area to teach, raise the profile of the service, encourage further research and apply evidence-based nursing directly back into patient care.</p> <p>This is a first in this area of inherited cardiac care and one that once again demonstrates what can be achieved in imaginative service development.</p> <p>Youth Cricket Initiatives</p> <p>The Trust has previously provided funding for youth wicket-keeping development programmes with both Surrey and Hampshire county cricket clubs. The Surrey programme focused on excellence and three attendees of the programme have become professional county cricketers. The Hampshire programme was more inclusive, giving the opportunity for specialist coaching to boys and girls from all age groups, supported by a "coach the coaches" initiative to promote a sustainable approach.</p>
<p>Public Benefit statement</p>	<p>The objects of the Trust are realised through the making of grants to appropriate organisations. The Trustees confirm that they have reviewed the Trust's aims and objectives and all activities having regard to the guidance issued by the Charity Commission on public benefit.</p>
<p>Policy on grant making</p>	<p>The Trust achieves its objects through the making of grants to other organisations. Grants will not be made to individuals.</p> <p>Monies raised will be held in unrestricted funds for grant making in accordance with the Trust's objectives unless the donor has indicated that they should be used for a specific purpose, in which case they will be allocated to a designated fund and only used for that purpose.</p> <p>Full funding must be secured and available before any commitment is made to expenditure on grants or other charitable activities.</p>

Section C

Achievements and performance

Summary of our main achievements, identifying the difference our work has made to the circumstances of our beneficiaries and any wider benefits to society as a whole	Children with Arrhythmia <p>The main focus for the year under review was the establishment of the new nurse consultant post at the Brompton. This was successfully achieved, with the new role taking effect from July 2019.</p> <p>The last decade has seen an increased awareness and understanding of inherited cardiac conditions by the medical community. Such conditions can result in a seemingly well young person succumbing to sudden death or cardiac arrest. Many of these conditions are treatable, but historically they have been very poorly recognised and consequently unmanaged. High profile cases have increased public awareness and people potentially at risk need rapid access to multidisciplinary expertise to help manage the impact and risk of their conditions.</p> <p>The support provided by Trust has helped the Brompton to build its service during this time from a very rudimentary clinic to a large, comprehensive, multidisciplinary service recognised nationally and internationally for the work that it does.</p> <p>Helped by the Trust's seed-corn funding for the first dedicated specialist nurse to work with medical teams and families, the Brompton's specialist nursing team has now grown to nine, serving both children and adult patients. Many families also benefit from the Brompton's dedicated counselling and psychological service that the Trust's funding has helped to establish. Very few other hospitals around the country can boast such a service.</p> <p>The development of genetic understanding is progressing rapidly. To harness its potential, the Brompton has invested in an on-site genetics and genomics centre and is one of the first services to offer multidisciplinary working across genetic scientists, specialist nurses and medical staff. This has transformed understanding and will further enhance the care that the team is able to provide for its patients and others in the UK.</p> <p>The nurse consultant is the first such appointment in children's inherited cardiac care area in the country. Our vision is that this novel approach to clinical leadership will bring huge benefits to families with inherited cardiac conditions through innovation, backed up by teaching and research, which we foresee driving improvements in care.</p>
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Section D

Financial review

Brief statement of the charity's policy on reserves	<p>The charity's current reserve of £182,672 has been accumulated in anticipation of future activity in support of children with arrhythmia and youth cricket initiatives.</p> <p>Since the end of the period under review, the Trustees have committed to fund a new nurse consultant role at the Royal Brompton Hospital. The grant is conditional upon the service being provided in accordance with the agreement, up to a maximum commitment of £150,000 over a two year period.</p>
Details of any funds materially in deficit	There are no funds in deficit.

<p>Principal sources of funds and expense policy</p>	<p>Funds are raised through a combination of voluntary donations, sponsorship of challenges undertaken by trustees and supporters of the charity, and fundraising events organised by the charity. The charity does not actively seek to raise funds through public collection, and does not use the services of paid fundraisers.</p> <p>It is the policy of the Trust to operate off as low an administrative cost base as possible and to ensure that all money spent in furtherance of its objects is very closely targeted to causes that meet its reason for existence.</p>
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Section E Structure, governance and management

Description of the charity's trusts

<p>Type of governing document</p>	<p>Trust Deed, dated 10 October 2006</p>
<p>How the charity is constituted</p>	<p>Unincorporated Trust</p>
<p>Appointment of new trustees</p>	<p>New trustees are appointed by the existing Trustees in Special meeting. Trustees are selected on the basis of:</p> <ul style="list-style-type: none"> • The contribution that they are able to make by virtue of their expertise, experience and commitment to the cause of the Ben Williams Trust • Their belief in the core principles of openness, transparency and integrity that underpin all Trust activity <p>The Trust's legal advisors draw the attention of prospective new trustees to the Charity Commission guidance on the responsibilities of Trustees prior to their acceptance of the role. New Trustees also receive a copy of the Trust Deed.</p> <p>The Charity Commission and other bodies from time to time issue regulatory updates and advisory guidance to Charities. The implications of such updates and guidance are discussed at Trustees' meetings</p>
<p>Major risks</p>	<p>The Trustees consider that the major risks to the charity are currently:</p> <ul style="list-style-type: none"> • NHS England Congenital Heart Disease (“CHD”) Review. Following a review by NHS England of CHD services for adults and children (“the Review”), the Brompton is required to complete a number of actions, without which it may be required to discontinue certain key activities supported by the Trust's funding. The Brompton has detailed action plans to meet the Review's requirements and as part of the process for awarding the new Nurse Consultant grant, the Brompton has confirmed that there is no known material threat to the continued provision of its paediatric cardiac services over the next three years including as a result of failing to meet the requirements mandated by the Review. • Fiduciary. The Trust's predominate asset is cash at bank, protected by the Financial Services Compensation Scheme. In the opinion of the Trustees, the financial controls in place safeguard cash receipts and payments. An independent examiner reports on the Trust's affairs on an annual basis.

Major risks (continued)	<p>Major Risks</p> <ul style="list-style-type: none"> • Reputational. The Trustees at all times adhere to the core values of openness, transparency and integrity. All fundraising events are designed with equal weighting to raise money for the Trust and to provide a safe and enjoyable experience for the participant. • Safeguarding. The Trust and its representatives have no direct day-to-day contact with children or other vulnerable individuals. In the event that fundraising or other activities involve such contact, the risk assessment will include consideration of safeguarding. • Public Liability. Risks of bodily injury or damage to non-owned property arising from fundraising activities are mitigated by risk assessments and insurance. • Medical Advice. The Trust does not offer medical advice.
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Section F Declaration

The Trustees declare that they have approved the Trustees' Report above.

Signed on behalf of the charity's trustees:

Signature:		
Full name:	Philip Stanhope Ray Williams	Deborah Anne Grimwood
Position:	Chair	Secretary
Date:	13 November 2019	13 November 2019