



Trustees' Annual Report for the period



The Ben Williams Trust
children with arrhythmia youth cricket initiative

Period start date		Period end date		
From	Day	Month	Year	To
	1	April	2016	31
		March	2017	

Section A Reference and administration details

Charity name The Ben Williams Trust

Other names charity is known by The Benjamin Williams Trust

Registered charity number (if any) 1116627

Charity's principal address Crofton

Park Road

Haslemere

Surrey

Postcode

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	Haslemere Branch, 24 High Street, Haslemere, Surrey GU27 2HN
Independent Examiner	Andy McAllister CA(SA)	6 Kingsley Road, Pinner, Middlesex HA5 5RB

Section B Structure, governance and management

Description of the charity's trusts

Type of governing document	Trust Deed, dated 10 October 2006
How the charity is constituted	Trust
New Trustees	<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 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>
Major Risks	<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. The Trust's major activity is to fund the development of new specialist posts within the NHS to support children with arrhythmias and their families. This funding has been directed to the Royal Brompton Hospital Trust (RBHT). NHS England is currently undertaking a review of CHD services for adults and children ("the Review") with one possible outcome being the discontinuation of RBHT's paediatric services. There is a consequent risk that the Trust provides funding for activities that are discontinued. The Trustees have therefore decided to suspend further funding initiatives until the outcome of the Review and its likely impacts are known. • Fiduciary. The Trust's assets are predominantly cash at bank. These funds are subject to the protection of the Financial Services Compensation Scheme. In the opinion of the Trustees, the financial controls in place safeguard cash receipts and payments. • 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. • 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.

<p>Summary of the objects of the charity set out in its 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>
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<p>Summary of the main activities undertaken for the public benefit in relation to these objects</p>	<p>Statement on Public Benefit</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>Paediatric cardiac electrophysiology nurse specialist post at the Royal Brompton Hospital Trust ("RBHT"), London</p> <p>The Trust funded the creation of a new paediatric cardiac electrophysiology nurse specialist post at RBHT, London, 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 groundbreaking 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 practitioner, helping to significantly improve the outpatient experience.</p> <p>After being supported by the Trust for three years from April 2008 to March 2010, the post now has statutory funding and is seen as a role model for the development of RBHT's cardiac nurse specialist service.</p> <p>Paediatric cardiac clinical psychologist post at the RBHT, London</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
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<p>Summary of the main activities undertaken for the public benefit in relation to these objects (continued)</p>	<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> <p>As a result of the value that the post delivered, it now receives statutory funding and is seen as a core component of RBHT's service provision.</p> <p>Wicket-keeping Development Programmes</p> <p>The Trust has 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 has been 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>
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Section D Achievements and performance

<p>Summary of the main achievements of the charity during the year</p>	<p>Support for children with arrhythmia</p> <p>The roles initially funded by the Trust and now supported by statutory funding continue to form a core component of RBHT's service provision.</p> <p>The Trustees have been working to develop a new nursing post at RBHT with a particular focus on those transitioning from paediatric to adult services, and has funds available for this purpose.</p> <p>However, as noted earlier within the report, NHS England is currently undertaking a review of CHD services for adults and children ("the Review") with one possible outcome being the discontinuation of RBHT's paediatric services. Whilst the Trustees are continuing to engage with RBHT over the development of the new post, they have decided to suspend commitment to funding until the outcome of the Review and its likely impacts are known. It is anticipated that this will be by the end of 2017.</p> <p>If the future of RBHT is then uncertain, the Trustees will undertake an assessment to determine how best to further the Trust's objectives within NHS England's post-Review paediatric CHD service delivery model.</p>
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Section E Financial review

Brief statement of the charity's policy on reserves	<p>It is the charity's policy not to commit to expenditure on charitable or other activities until matching funds are available. The charity's current reserve of £112,461 has been accumulated in anticipation of future activity in support of children with arrhythmia and youth cricket initiatives.</p> <p>As noted elsewhere within this report, the Trustees are currently investigating funding an additional nurse specialist role with a focus on patients transitioning from childhood through adolescence and into adulthood. Should this progress, the likely amount required will be £100,000.</p>
Details of any funds materially in deficit	There are no funds in deficit.
Principal sources of funds and expense policy	<p>The principal sources of 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>

Section F Declaration

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

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Philip Stanhope Ray Williams	Deborah Anne Grimwood
Position (eg Secretary, Chair, etc)	Chair	Secretary
	09/12/2017	09/12/2017