



# Trustees' Annual Report for the period



The Ben Williams Trust  
children with arrhythmia youth cricket initiative

		Period start date			Period end date		
<b>From</b>	Day	Month	Year	<b>To</b>	Day	Month	Year
	1	April	2015		31	March	2016

## 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 of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year
None	

### Names and addresses of advisers (Optional information)

Type of adviser	Name	Address
<b>Solicitor</b>	Hart Brown	Resolution House, Riverview, Walnut Tree Close, Guildford, Surrey GU1 4UX
<b>Banker</b>	NatWest	Haslemere Branch, 24 High Street, Haslemere, Surrey GU27 2HN
<b>Independent Examiner</b>	Andy McAllister CA(SA)	10 Weysprings, Haslemere, Surrey GU27 1DE

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

None

## Section B Structure, governance and management

### Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	Trust Deed, dated 10 October 2006
How the charity is constituted (eg. trust, association, company)	Trust
Trustee selection methods (eg. appointed by, elected by)	<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"> <li>• The contribution that they are able to make by virtue of their expertise, experience and commitment to the cause of the Trust</li> <li>• Their belief in the core principles of openness, transparency and integrity that underpin all Trust activity</li> </ul>

### Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

#### Induction and Training

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.

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.

#### Major Risks

The Trustees consider that the major risks to the charity are currently:

- **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.
- **Changes within the NHS.** The Trust's major activity is to fund the development of new posts within the NHS to support children with arrhythmias and their families. The continuing agenda for change in the NHS, particularly within the area of Congenital Heart Disease, creates a risk that the Trust funds a role that becomes a casualty of that change. As a condition of funding for any new post at the Royal Brompton Hospital, the Trustees will where possible seek a guarantee the hospital will adopt the post after the designated period of funding.

**Summary of the objects of the charity set out in its governing document**

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.

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.

The Trust has been set up in Ben's memory. Its objects are:

- To relieve sickness and preserve the health of children and young people suffering from heart muscle disorders, for example by:
  - 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;

Whilst the cricketing related objects of the Trust are broad, the Trustees are most keen to support the development of young wicket-keepers.

**Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)**

#### **Statement on Public Benefit**

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.

#### **Paediatric cardiac electrophysiology nurse specialist post at the Royal Brompton Hospital, London**

The Trust funded the creation of a new paediatric cardiac electrophysiology nurse specialist post at the Royal Brompton Hospital, London, known as "Ben's Nurse". After being supported by the Trust for three years from April 2008 to March 2010, the post now has statutory funding and has been seen as a role model for the development of the Royal Brompton's cardiac nurse specialist service.

#### **Paediatric cardiac clinical psychologist post at the Royal Brompton Hospital, London**

As a natural extension of the nurse specialist post and as detailed later in this report, the Trust has funded the creation of a new clinical psychology post for two years from 1 April 2014 to 31 March 2016. Working as part of the multi-disciplinary paediatric Inherited Cardiac Disease team, the role promotes psychological well-being, offers support and helps 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. The post also included an element of research into how the provision of psychological support can be improved, with proactive rather than reactive intervention.

#### **Wicketkeeping Development Programmes**

The Trust has in past years provided funding for youth wicketkeeping development programmes with both Surrey and Hampshire county cricket clubs. No such activity was funded in the year under review, but it is anticipated that the Hampshire programme will resume for winter 2016/17.

#### **Additional details of objectives and activities (Optional information)**

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

**Summary of the main achievements of the charity during the year****Activities Undertaken for the Public Benefit****Paediatric Clinical Psychologist**

The post of Ben's Nurse has been fully established as a key component of the children's cardiac electrophysiology services provided by the team at the Royal Brompton. It now receives statutory funding and has been a role model for the expansion of the Royal Brompton's cardiac nurse specialist service.

With effect from 1 April 2014, Dr Hannah Levy was appointed as the Ben Williams Trust paediatric clinical psychologist at the Royal Brompton Hospital. Hannah has worked alongside the current team of professionals with children and their families to promote psychological well-being, offer support and to help with any psychological problems that may arise. As with Ben's Nurse, the aim is to help those impacted to live as normal a life as possible. Hannah is also undertaking research into how the provision of psychological support can be improved, with proactive rather than reactive intervention.

Examples of situations where the clinical psychologist can lend valuable support include:

- 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

At 1 April 2016, with the role having become well established and seen as an important component of the Royal Brompton's paediatric cardiac service, it has been absorbed within statutory funding by the Royal Brompton.

## Section E

## Financial review

### Brief statement of the charity's policy on reserves

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 £93,340 has been accumulated in anticipation of future activity in support of children with arrhythmia and youth cricket initiatives.

The Trustees are currently investigating funding an additional nurse specialist role with a focus on patients transitioning from childhood through adolescence and into adulthood. The likely amount required will be £100,000.

### Details of any funds materially in deficit

There are no funds in deficit.

### Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

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.

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.

## Section F

## Other optional information

## Section G

## 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
Date	10 December 2016	10 December 2016