



*The Ben Williams Trust was founded in 2006 following Ben's death at the age of 14 from a rare heart muscle disorder. The Trust provides funding to support children and young adults who are suffering from arrhythmias (abnormal heart rhythms), to help them and their families live as normal a life as possible. It is currently funding a specialist physiotherapy post on the paediatric electrophysiology and inherited cardiac conditions team at the Royal Brompton Hospital. It has previously funded the creation of three ground-breaking specialist posts: a nurse specialist, a clinical psychologist and a nurse consultant. The success of these roles has resulted in them all attracting mainstream NHS funding, and they are seen as role models as the service expands.*

*The Trust has also supported youth cricket with a particular emphasis on wicket-keeping.*

## Chair's message

### Introduction

We are delighted to announce the creation of a new physiotherapy post at the Royal Brompton Hospital. Cat Barraclough is working alongside the multi-disciplinary paediatric arrhythmia team, providing individually tailored and targeted exercise and activity programmes to children with arrhythmia. The Trust will fund the post for 18 months, with the intention being that it is then absorbed into statutory funding.

The cost of supporting the post will absorb every penny of our remaining funds, and we therefore feel that this is the right time to wind down the Trust.

When we started the Trust 18 years ago, we wanted to help improve the support available to children like Ben, who receive life-changing arrhythmia diagnoses, and their families. We feel that we achieved a great deal. With your support we have helped the Royal Brompton to grow their nationally and internationally recognized multi-disciplinary team, including dedicated specialist nurses, a clinical psychologist, a nurse consultant and now a physiotherapist.

We are also pleased to see two of the young cricketers we have supported go on to play for England.

Every single donation we have received, of whatever size, has helped us to raise £500,000. Nearly 99% of this has gone directly to our supported causes.

We are very grateful for your amazing support over the years, which has made all of this possible.

### The New Physiotherapy Post

Physical activity is vital for health and wellbeing, but children with arrhythmia and their parents are often highly anxious about exercise. Parents are often unsure how their child can exercise safely within the limits of their underlying condition, medication, and any fitted cardiac devices such as a pacemaker or Implantable Cardioverter Defibrillator. The fear of triggering a sudden change in rhythm that may threaten life or require a visit to hospital can be paralysing, make anxiety worse and result in children being excluded from social peer groups.

Cat Barraclough is a highly specialist physiotherapist with considerable experience in arrhythmias. She has worked in many different areas within the paediatric field with a focus on patients with lung and heart conditions. Being a keen runner, hockey enthusiast and having two young children herself, she is passionate about keeping children

active and healthy through participation in exercise, activity and sport from early years right up to adulthood.



*Cat Barraclough*  
*Physiotherapist*

Cat says: "I hope to improve the physical functioning and quality of life for this group of children. In addition, I hope to raise awareness of this group of conditions, promote exercise participation for the benefit of physical and psychological health and be a forerunner to enable others to set up services nationally and internationally".

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## Our Previous Posts

### Ben's Nurse

The first Trust-funded role was the creation of a new paediatric cardiac electrophysiology nurse specialist post, known as "Ben's Nurse". The post allowed children with arrhythmias 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.



Catherine Renwick, Ben's Nurse

### Clinical Psychologist

As a natural extension of the nurse specialist post, the Trust funded the creation of a new clinical psychology post. 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 affected to live as normal a life as possible.

### Nurse Consultant

The Nurse Consultant is a highly qualified and skilled nurse, with clinical responsibility for acute, long term and more complex cases, and for providing expert support and advice to nursing staff in patient care. The Nurse Consultant also takes an active role in research, leading the development of patient services and raising the profile of the team and its work, both within the Royal

Brompton Hospital and in the wider national and international healthcare community.

This is one of very few such posts, recognising the highly specialist nature of the role and the level of expertise required.

### Wicket-keeping Coaching

The Trust has funded two County youth wicket-keeping coaching programmes.

#### Surrey Elite Programme

The Surrey Elite programme, which ran from 2007 to 2013, focused on wicket-keeping excellence, with the coaches including Trust patrons Alec Stewart and Jon Batty.

Two of the attendees, Rory Burns and Ollie Pope, have gone on to represent England at test level, with Ollie having kept wicket on three occasions. The third attendee, Michael Burgess, has made a career as a wicket-keeper - batter on the county circuit, playing for Leicestershire, Sussex and Warwickshire.

#### Hampshire Programme

The Hampshire programme, which ran from 2008 to 2015, was more community focused, giving the opportunity for specialist coaching for up to 60 boys and girls each year from all age groups, supported by a "coach the coaches" initiative to promote a sustainable approach.



Ben Williams  
Surrey Under 14s  
Perth, Western Australia, 2004

## Some Fundraising Highlights

There have been many memorable moments and fundraising events over the last 18 years. These include the Oval Dinner, Jig for Victory, Greasewood, Seventies Night Fever, Memorial Cricket Matches, Christmas Sales and sponsored walks in the Lake District, Wales and on Blackdown. Events arranged by our supporters include the Grayswood CC Chairman's Ball, Loseley House Concert, Big Band and Jazz performances, Book Days and a variety of sales. Walkers, marathon runners, cyclists, swimmers, "Tough Mudders", anglers and parachutists have been as far afield as Everest Base Camp, Kilimanjaro, France, and Ben Nevis.

We hope that participation in all these different events has left many happy memories as well as having helped to make a real difference for the children and families who have benefited from the funding these activities have generated.



BWT at Kilimanjaro Summit,  
Everest Base Camp & Ben Nevis