



*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 has funded the creation of three ground-breaking specialist posts in paediatric electrophysiology and inherited cardiac conditions at the Royal Brompton Hospital: a nurse specialist, a clinical psychologist and most recently a nurse consultant post. 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 also supports youth cricket with a particular emphasis on wicket-keeping.*

## Chair's message

### Introduction

2023 has seen us continuing in our efforts to create a new physiotherapy post at the Royal Brompton Hospital. The aim of the post is to provide specialist rehabilitation support to children with arrhythmia, including those with a pacemaker or defibrillator, with tailored exercise programmes. Participation in exercise programmes will benefit both the physical and mental health of those taking part.

At the time of writing, the post has been approved, with the Ben Williams Trust providing funding for an initial period of 18 months, and it is hoped that the appointee will be in place in Spring 2024.

Thanks again to everyone who has supported us financially and in other ways this year and over the past 17 years, helping us to raise almost £500,000 for our good causes.

### Our 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.



#### 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. The Surrey Elite programme focused on excellence and two attendees, Rory Burns and Ollie Pope, have gone on to represent England at test level.

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.

#### Our Contact Details:

Crofton  
Park Road  
Haslemere  
Surrey GU27 2NL  
t: 01428 652582  
e: info@benwilliamstrust.org.uk  
w: www.benwilliamstrust.org.uk