



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

2022 has been a relatively quiet year for the Trust, as we continue to develop opportunities for future projects with the team at the Royal Brompton hospital. Budgetary and other pressures can make this a frustratingly slow process at times, but we remain in discussion about a physiotherapy post to provide specialist rehabilitation support. This would better equip children, including those with a pacemaker or defibrillator, by providing them with tailored exercise programmes.

Once again, as our fundraising activities have of necessity been severely curtailed by the pandemic, this year's newsletter offers a brief reminder of the key projects that we have funded over the last 16 years. Thanks again to everyone who has supported us financially and in other ways over this time, and helped us to raise almost £500,000 for our good causes.

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 Thanks

We would like to pass on our special thanks to the Bullock Family Trust and to Surbiton Hockey Club for their generous donations.

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