



*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 two groundbreaking new posts at the Royal Brompton Hospital, a paediatric electrophysiology nurse specialist and a clinical psychologist. The success of these roles has resulted in them attracting mainstream NHS funding, and further similar roles being introduced. The Trust also supports youth cricket with a particular emphasis on wicketkeeping.*

## Chairman's message from Phil Williams

**A**t the time of writing we are making very good progress towards the creation of our third groundbreaking new post at the Royal Brompton, that of Nurse Consultant.

In this edition Dr Jan Till describes how children's cardiac services at the Royal Brompton have developed over the last 12 years, and the role that the Ben Williams Trust played in this. We also catch up on the progress of two of the young Surrey cricketers who attended the Trust funded elite wicket-keeping programme.

This year saw us reach the milestone of raising £400,000 for our nominated causes. Thank you for making this possible and for all your support.

### Working with the Brompton

Dr Jan Till has provided the following update from the Royal Brompton.

"The last decade has seen an increased awareness and understanding of inherited cardiac conditions. Sadly, such conditions can result in a seemingly well young person succumbing to sudden death or cardiac arrest. Many of these conditions are treatable, but historically they have been very poorly recognised and consequently have not been managed."

"People at risk need rapid access to multidisciplinary expertise to help manage the impact and risk of their conditions. It is important that an inherited cardiac condition service is able to offer psychological as well as good medical support.

"The Ben Williams Trust's support has helped us to build our service from a very rudimentary clinic to a large, comprehensive, multidisciplinary service recognised nationally and internationally for the work that we do."

"The Ben Williams Trust kick-started funding for a dedicated specialist nurse to work with medical teams and families at the beginning of our journey and our specialist nursing team has now grown from one to nine, serving both children and adult patients. Many families benefit from counselling and psychological assistance and again the Ben Williams Trust has allowed us to welcome a dedicated psychologist to the team. Very few other institutions around the country can boast such a service."

"Our next venture will again be innovative and with the help of the Ben Williams Trust we plan to appoint a Nurse Consultant, the first such appointment in the country. Our vision is that this novel approach to clinical leadership will bring huge benefits to families with inherited cardiac conditions through innovation, backed up by teaching and research, which we foresee driving improvements in care."

"In parallel to the development of our team, genetic understanding is progressing rapidly. The Royal Brompton has invested in an on-site genetics and genomics centre and will be one of the four national cardiac

genetic testing centres in the UK. As a result, we are one of the first services to offer multidisciplinary working across genetic scientists, specialist nurses and medical staff. This has transformed our understanding and will further enhance the care we are able to provide for our patients and others in the UK."

"All this work is vital and makes life once again possible for the many families who find themselves affected with inherited cardiac conditions. We are entirely grateful for the funding raised by you for our service and families we care for. We know it makes a huge difference to the quality of care we can offer."

### Dr Jan Till

Dr Jan Till, a Patron of the Trust, is a consultant paediatric electrophysiologist based at the Royal Brompton Hospital, London.



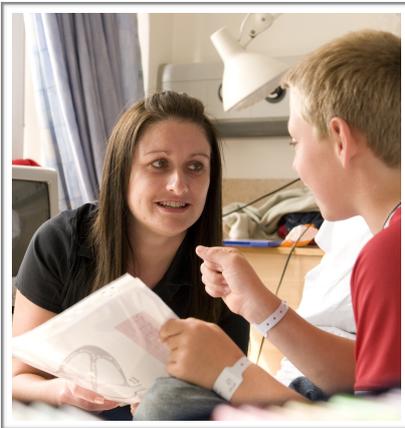
She is also Divisional Director of Children's Cardiac Services and Co-director of Paediatrics. She leads one of the largest services nationally offering specialist support and provision for children with heart rhythm irregularities.



## Nurse Consultant

As Jan has referred to, we are currently working with the Royal Brompton Hospital to create a Nurse Consultant post for the inherited cardiac care team, with the aim of delivering further improvement in patient care and understanding of individuals' conditions.

The post holder will be an expert in their field, driving excellence through service leadership, direct patient care, research and education, without many of the management responsibilities generally associated with roles of this level of seniority.



*Catherine Renwick, our first nurse specialist appointment*

The Nurse Consultant will devote at least half of their time to clinical work, focusing on acute, long term and more complex cases, and providing expert support and advice to nursing staff in patient care delivery.

Equally important will be using their academic achievement and exceptional knowledge and skills in this highly specialised area to teach, raise the profile of the service, encourage further research and apply evidence based nursing directly back into patient care.

This will be a first in this area of inherited cardiac care and one that would once again demonstrate what can be achieved in imaginative service development.

## Where are they now?

For six seasons from 2007/8 to 2012/13 the Trust funded intensive elite winter training programmes for young Surrey wicket-keepers, with Trust patrons Alec Stewart and Jon Batty taking a leading role in the coaching.

We are delighted that two attendees of the programme have gone on to receive international honours this



*Michael Burgess, Jon Batty and Rory Burns in 2009*

year. **Rory Burns** has just led Surrey to the County Championship, finishing the season as the Championship's leading run scorer, and being rewarded with his first England cap against Sri Lanka in Galle in November 2018. **Ollie Pope** made his test debut at Lord's for England against India in August 2018 after playing only 15 first class matches. He scored four Championship centuries for Surrey this season and in October was awarded the PCA Young Player of the Year award.

In addition, **Michael Burgess** has been a regular for Sussex this season in all formats of the game.

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## Fundraising

Thanks to the collective efforts of Trust supporters, we have now reached the milestone of having raised **£400,000** towards our nominated causes.

In addition to the many individual contributions made this year, we would like to thank Surbiton Hockey Club and Grayswood Cricket Club for their continuing support.

## Christmas Sale

The 2017 Christmas sale was another great success, raising over £3,600 for the Trust. Whilst thanks are due to everyone who supported the event, special mention needs to be made of Clare Taylor, who has led the team of wreath makers for the last 11 years. During this time, Clare and her team have made close on 500 wreaths and directly raised £12,500. They have also played a key role in our Christmas sales over this period which have in total generated over £25,000 for the Trust. After making 60 wreaths for the 2017 sale in some of the coldest conditions on record, Clare is taking a well earned retirement, and we would like to give her our very special thanks for her massive contribution.

## How to donate

There are a number of different options for making a donation. For ad-hoc amounts, send us a cheque or make a bank transfer straight into our account - let us know and we will give you have the details. Alternatively, you can make a payment on-line through JustGiving at [justgiving.com/benwilliamstrust](http://justgiving.com/benwilliamstrust), for which they will charge us a small fee. To make a regular donation, we suggest setting up a standing order into our account. Alternatively, your employer may have an approved payroll giving scheme such as that operated by Charitable Giving that enables you to make payments directly out of your salary.