



*"I think of Ben a lot as we have a number of young people who I have had to give the diagnosis of ARVC to this last year. Some of them have been very sick and it has been a terrible struggle for them. ARVC is most definitely very cruel in its onset at an age when they are just going through those teenage years. They have very much benefitted from our specialist nurse and psychology team."*

*Jan Till, Consultant Paediatric Electrophysiologist, Royal Brompton*

## Chairman's message from Phil Williams

**2016** marked the tenth anniversary of Ben's death in February 2006, and the creation of the Ben Williams Trust in his memory. This seems an appropriate time to celebrate what has been achieved over the last ten years and the difference it has made to the lives of children and their families affected by arrhythmia.

Our objective in setting up the Trust was to help support children and their families undergoing investigation for arrhythmia and having to cope with all the implications of a positive diagnosis, both for the child and for the wider family. We knew from first hand experience how traumatic this can be, especially where a child is at risk of sudden death.

We were also aware that the lifestyle of affected children was being unnecessarily impacted, for example with children being excluded from schools unwilling to take the risk of an episode on their premises.

With the aim of helping children and their families to live as normal a life as possible, the Trust has funded the creation of two specialist posts at the Royal Brompton Hospital. The first was Ben's Nurse, a paediatric cardiology electrophysiology nurse specialist, and the second a specialist clinical psychologist. Both roles proved their value within a very short period of time and have been adopted into mainstream funding.

The team at the Brompton has grown significantly in size and capability since the creation of Ben's Nurse, and the two roles that the Trust has funded have been instrumental in that development. Both are seen as role models for future service provision.

We are indeed fortunate to be able to work with such talented and dedicated professionals as Catherine Renwick, Hannah Levy and Chantell Douglas.

We would like to thank Dr Jan Till, Lizzie Biggart and Michelle Puckey for their support and guidance over the last ten years.

### Stumper's View

The Trust has also supported the development of young wicketkeepers at both Surrey and Hampshire cricket clubs, reflecting one of Ben's great passions in life.

Under the guidance of Trust patrons Alec Stewart and Jon Batty, the Surrey programme has delivered an elite wicketkeeping programme for two boys each year over a six year period.

The Trust has also funded Hampshire's wicketkeeping coaching programme since 2009. In addition to providing an opportunity for specialist coaching for over 40 boys and girls each year, the programme led by Bobby Parks has cascaded coaching skills throughout the club coaching community.

### What's Next

We continue to work with the team at the Brompton to flesh out the details

of the next and third post, and have set aside £100,000 in anticipation of this. We will also be continuing to work with Hampshire to develop the youth wicketkeeping programme.

### And finally...

None of this could have happened without your support. Please read on...

### The Professionals



Catherine Renwick, Nurse Specialist



Hannah Levy, Clinical Psychologist



Chantell Douglas, Maternity cover for Hannah

## Fundraising

The collective efforts of Trust supporters have enable us to raise £370,000 towards our nominated causes. This has been achieved by many people giving up their time, hard graft, blood, sweat and tears, and, of course, their hard earned cash. We are very grateful to you all, and hope that you think that your efforts have been worthwhile. We also hope that you have had some fun along the way - we certainly have.

There is simply too much to cover in one newsletter, but what follows is the highlights of the last year and a bit of a trip down memory lane.

## South Downs Walk

To mark the occasion of Ben's 25th birthday Gilly, Phil and Jonathan walked (or in Phil's case hobbled) 25 miles from Steyning to Cocking along the South Downs way in 9 1/2 hours, raising £9,000 for the Trust.

The weather was kind, and the challenge became a grand day out thanks to the refreshments and moral support provided by the support crew at the two stops, and a team who accompanied the weary walkers for the last seven miles to make sure they made it home for a celebratory supper.



Many thanks to Jane, Huw, Debbie, Paul, Bridget, Steve, Jenny, Nigel, Lucy, Jamie, Caroline, Will, Emily, Dizzy and Bob for your help and support.



## Lucy's 50th

Following on from accompanying Gilly and Phil on training for the South Downs challenge, and walking with them on the last leg, Lucy and Jamie climbed Ben Nevis in July to mark Lucy's 50th birthday, along with Alfie and Megan. They raised over £650 for the Trust in the process.



## 2015 Christmas sale

The 2015 Christmas sale was another great success, raising nearly £3,000. Thanks are due to everyone involved, but particularly once again to Clare Taylor and her team for making and selling 55 wreaths.

The Ben Williams Trust  
Crofton, Park Road  
Haslemere  
Surrey GU27 2NL  
t: 01428 652582  
e: [info@benwilliamstrust.org.uk](mailto:info@benwilliamstrust.org.uk)  
w: [www.benwilliamstrust.org.uk](http://www.benwilliamstrust.org.uk)



## Do you remember?

Some of the highlights of the last ten years:

- The dinner at the Brit Oval, with Jonny Gould, Mark Nicholas and a guest appearance from Strictly winner Mark Ramprakash, raising over £65,000
- A grant of £73,000 from the Burdett Trust for Nursing
- Opera in the Great Hall at Loseley Park and Jazz at the RGS



- Jig for Victory, Seventies Night Fever and Greasewood at Grayswood Village Hall
- Sponsored walks in the Lake District, Black Mountains, Yorkshire Three Peaks and South Downs National Park
- Ascents of Kilimanjaro and Ben Nevis; trekking to Everest base camp
- Marathons, cycle rides, parachute jumps, swims, tough mudders, runs



long walks and fishing

- Christmas sales, charity sales and the South Harting book swap
- Memorial cricket matches on Grayswood village green.

## Thank you

also to Sir Jules Thom Charitable Trust, Chaucer, Surbiton Hockey Club, and the Remarkable Studio.