

# Newsletter

MARCH 2021

# HEART HEROES

## ELLA'S STORY

### LIVING WITH A CONGENITAL HEART CONDITION:

When Chantelle and Ryan Ball welcomed their baby daughter into the world, their family was complete.

The couple's son Cody, then four, was thrilled to have a baby sister to help look after. Chantelle and Ryan had the son and daughter they had dreamed of.

Chantelle sailed through her pregnancy and all seemed well. Ella was due for arrival on Christmas Eve, came a week later on New Year's Eve, and the labour and delivery were textbook.

"Cody was super excited about being a big brother and we were thrilled our family was now complete," says Chantelle. "Everything was going well and we took Ella home to start our new life as a family of four."

Ella proved to be a dream baby. She slept brilliantly, going down at 7pm and waking just once during the night. The only slight concern was how long she took to feed, taking in only a few ounces of milk at a time. This was commented on by the health visitor, but it was dismissed as probable reflux and in every way Ella seemed healthy.

Life moved on. Ella remained small but Chantelle herself is petite, so still no alarm bells were triggered.

It was in the November before Ella's first birthday that things started to go wrong. Ella developed croup and struggled to breathe, so much so that she was hospitalised.

Appearing better, and following treatment with steroids, Ella was sent home. But Chantelle felt on edge, because Ella didn't seem to be improving and once again began struggling to breathe. An ambulance was called and she was back in hospital. Ella was treated and discharged, but at the same time referred to a consultant for a follow up.

Christmas and Ella's first birthday came and went and then came the family's appointment with the consultant.

Chantelle said: "We went along to the appointment at Bristol Children's Hospital thinking we were wasting their time, because apart from being a small eater and petite, Ella seemed fine. They did lots of tests and then out of nowhere a family liaison person was brought in and we were told she had a heart condition and needed heart surgery ASAP. In seconds we went from thinking all was fine to our world being totally rocked."

Ella had been diagnosed with subaortic stenosis, where the flow of blood from the heart's pumping chamber is restricted due to excess tissue.

Ella's first open heart surgery to remove the tissue took place in the summer. It was a five hour operation and she was just 18 months old.

Throughout the next year Ella thrived, but in the summer – following a minor bump to her head – Ella suffered convulsions. It transpired the heart tissue had regrown, which may have caused the convulsions. Ella had to face a second lot of heart surgery.

Now aged eight, Ella has been through open heart surgery four times. When she was five she had a seven hour operation during which a pacemaker fitted. She's since need a fourth round to replace the pacemaker and to fit a donor valve into her heart.

"It's devastating whenever she has surgery and we know she's not seen the last of it. In the future Ella will at least need the pacemaker changed and the donor valve replaced, because it won't grow with her. She also has a hole in the heart, which may need treating, so we just don't know what the future holds."

Ella is a bright, lively resilient girl who takes all the treatment in her stride. But even she finds she misses out. On one occasion when she wasn't allowed to go swimming due to treatment, she asked, 'Mummy why is the world so unfair?' It broke Chantelle's heart. After she has had a period in hospital, she will wake in the night saying she has dreamt she is still there.

"She's a wonderful little girl but she hasn't had the childhood we wanted for her, so we do as much as we can to make things special and wonderful for her and Cody."

Chantelle says Heart Heroes have been a big support to the family.

"It is a very lonely, isolating place, seeing your child on a drip and hooked up to all these machines. You wonder 'Why me? Why my child?' so when we came across Heart Heroes it really helped to be able to share and have support from people who knew and understood what we were going through.

"Heart Heroes really go above and beyond and they listen to the families about what we need."

At Heart Heroes we support children living with congenital heart conditions and their families, in Gloucestershire, Worcestershire, Bristol, Wales and across the South West.



## GIANT IPAD



New Investment for Dolphin Ward at The Children's Hospital Bristol

We have just made an exciting new investment – the Children's Cardiac Dolphin Ward will receive a 'giant iPad' from us: it is an interactive display, made by Sharp, and is on a child-friendly wooden stand with smooth corners and wheels so that it can have the maximum impact possible by reaching children all over the ward. It comes complete with lots of features that we hope will be both fun and useful for the children, such as games, Netflix, BBC iPlayer, puzzles, colouring apps, and more.

The device will prove invaluable in breaking up the monotony of being in a hospital, and we hope it will enable children to enjoy activities together and perhaps provide some educational value too. Its use is varied and flexible, hence why we believe it is a good investment that will remain effective for years to come.

We hope you can see that your donations go to great causes that have direct and tangible impacts on the lives of those children affected by heart conditions. Every bit of help, big or small, means that the suffering endured by the children and their parents is lessened through projects like these, enabling the children to play and have fun, as all children should.

A HUGE thank you to the team at Big Dug for their Heart Month Fundraiser which helped make this possible.

## CHARITY PARTNER



Heart Heroes chosen as charity partner for Perry Bishop's lettings team.

We are thrilled to lend our support to this wonderful charity who are making such a difference to the lives of children with heart conditions and their families.

Tammy Powell, Lettings Manager Perry Bishop

## RAFFLE

Our £1000 holiday RAFFLE. £5 per ticket, £20 for 5 tickets working with Not Just Travel-Nicky Pegram, Personal Travel Consultant.

We have now 2nd and 3rd prizes thanks to South West Upholstery Bristol.

Once all 500 tickets are sold we will draw the WINNER live on Facebook.

Contact us and send your payment to....  
<https://www.paypal.me/heartheroes>



Give as you Live<sup>®</sup> Online

Generate donations for us when you shop Easter treats online

Amazon eBay Next Iceland M&S Ocado Sainsbury's Aldi Waitrose



## A HEART HEROES EASTER

Our heart families will be taking in part in a virtual Easter Bunny Visit on Easter Saturday. Easter boxes have been sent and parents are being asked to hide the eggs during the event ready for the children to go and find. Our older Heart children will get an Easter eggs also. JB Event Hire very kindly ran a campaign collecting donated Easter eggs, thank you James and team.

# BALLOON RACE

We are very excited to be taking part in a virtual balloon race.

Balloons are £3 each and all monies to Heart Heroes, they can be designed by the children or adults themselves.

The Race starts on Good Friday April 2nd 12pm and ends on April 8th 2021 12pm.

<https://www.balloonrace.com/hearheroes>



Who wants to party the Dancin' Easy way?

## HeartHeroes Ball 25/9/21

# Free Online Course Counselling Skills



Do you want to up skill?  
Would you like to do a free course?  
Time on your hands?  
Stand out from the employment crowd...  
Go to our website for further information  
<https://hearheroesfreecourses.co.uk/>



We are very excited to be continuing with our Heart Heroes Roaring 20's Ball on September 25th. With 140 tickets sold already the team are busy planning the evenings entertainment and the band Dancing Easy along with By Jiminy the magician are looking forward to seeing everyone on the evening. Few tickets remaining, don't miss out get your ASAP.

# NOW LAUNCHED...

## HEART HEROES PODCAST



Request your **FREE** syndicate from today!

**All for one and one for all**

Why not start a **syndicate** today? An exciting way to support your local community as a team

- You have more chances to win with a syndicate
- Your support makes a HUGE difference to your community
- Need help? Contact your support team - details on the lottery home page
- It's a WIN WIN for us both - you could win up to £25,000 every week!

To start supporting, visit  
[www.gloucesterlottery.co.uk](http://www.gloucesterlottery.co.uk)  
and search for: Heart Heroes

Supporter website is available in Welsh.  
A syndicate is an informal agreement between the syndicate manager and the team. For a free syndicate document please call the support team. The number can be found on the lottery website.

## NEW SHOP ITEMS ADDED

Visit our shop [www.heartheroes.co.uk/shop](http://www.heartheroes.co.uk/shop)



SCAN ME

[www.heartheroes.co.uk](http://www.heartheroes.co.uk)



Working with the wonderful team at Heart Heroes we've collated together a special range of medical bracelets that we think you'll love.

Use the special code HEARTHERO to get 10% off your order and be sure to check back as we'll be launching exciting new designs very soon!



Celebrating 6 months since Amy, our Communications Assistant joined the Heart Heroes team. Amy goes above and beyond inside and outside of her normal working hours. Thank you Amy and Happy Birthday for April 1st.

## SEND THANK YOU E-CARDS

THANK  
YOU!

Switch to e-cards, help our charity, and save the planet. We've teamed up with DontSendMeACard where you can support our charity by giving what it would have cost to send cards. You can then send loved ones e-cards instead! Check out our e-cards (<https://www.dontsendmeacard.com/charities/151p8>)

## VIRTUAL RETREAT



19 Heart Parents have all been signed up to a **STRESS MANAGEMENT** course **ONLINE** which consisted of 1.5 hours of 15-20 min bitesize modules. Funded by Heart Heroes but made possible by the National lottery grant we've recently received.

Heart Mum Nicola said "Stress Management course completed. Thought it was really good and will definitely make use of the techniques suggested as can see feel the benefits when I do them."

Our next offering will be a **VIRTUAL RETREAT** - Retreat at home with Retreat in a Box - hamper and access to all online Head, Heart, Hara resources.

## JOIN OUR COMMUNITY



Our GiveHope community are a group of compassionate people just like you who are dedicated to changing lives for our Heart Heroes by donating regularly. Visit our website to find out more [www.heartheroes.co.uk](http://www.heartheroes.co.uk)

[www.heartheroes.co.uk](http://www.heartheroes.co.uk) | [email@heartheroes.co.uk](mailto:email@heartheroes.co.uk)

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