

Status: Official

NHSBT Board Meeting
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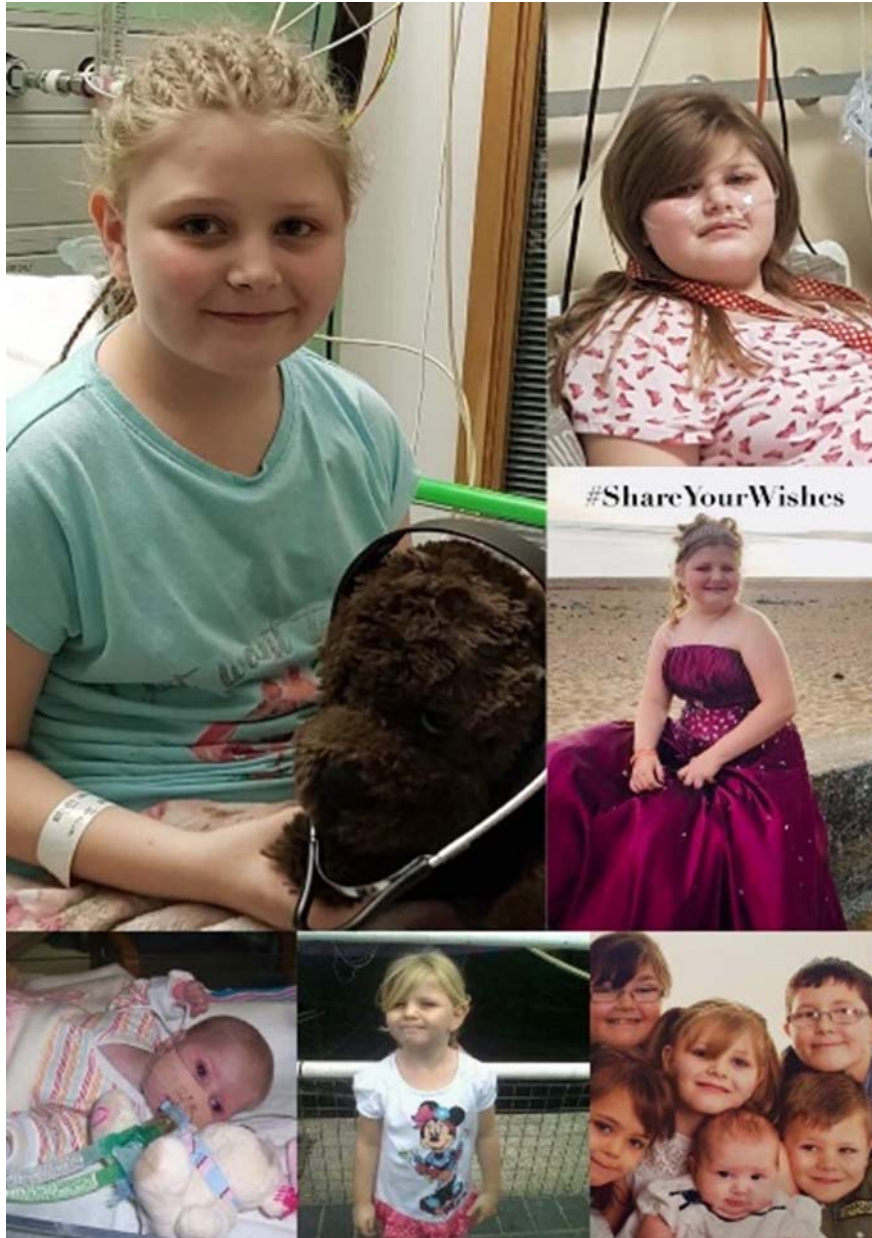
A Patient Story: Lilly Kendall, Heart and Lung Transplant Recipient

This is the story of Lilly Kendall who is 11 years old. She has 2 brothers and 3 sisters and lives in Llanelli, South West Wales.

When Lilly was 10 days old she became unwell, her mother became increasingly concerned that she was not improving and made the decision to take Lilly to her local hospital. There Lilly was examined by the medical team who diagnosed her with dilated cardiomyopathy, left heart syndrome and pulmonary hypertension, conditions which would require her to undergo immediate surgery. Her diagnosis was devastating news for Lilly's family and left them frightened for her future.

Lilly had surgery and then spent the next 3 months in Bristol Children's Hospital rehabilitating and recovering, she was then able to be discharged home where she led a relatively normal life for a period. In the Summer of 2017 Lilly attended the University Hospital of Wales in Cardiff for routine check-ups and tests. The specialists gave Lilly and her family the news that Lilly had significant changes in her cardiac and lung function. At this point Lilly was referred from Cardiff on to more specialists in Bristol where Lilly was told she needed to be assessed for a heart transplant. The assessment of suitability to be placed on the waiting list for a heart was undertaken at Great Ormond Street Hospital for Children. During this process in December 2017 Lilly collapsed and needed resuscitation. Lilly and her family were informed that her condition had changed to restrictive cardiomyopathy. This meant that the pressure in her heart was too high for a transplant, consequently the decision was made that she would not be placed on the transplant waiting list.

In January 2018, Lilly was also diagnosed with interstitial lung disease. This meant that Lilly now required a Heart and Lung Transplant. During January and October Lilly was assessed twice to be listed but could not be because of high pulmonary pressures.



In July 2018 Lilly's mum asked to talk to someone about organ donation, as Lilly was now placed onto a palliative care pathway due to her declining health.

Kathy, one of the Specialist Requestor's in the South Wales Organ Donation Services Team met with Lilly's mum in October 2018 to discuss the process of organ donation due to Lilly's worsening condition. She wanted to know if Lilly would be able to be a donor if she died because she was unable to be transplanted.



Kathy answered all the questions and it was then that Lilly's mum asked if Kathy would discuss organ donation with Lilly, as it was Lilly herself who had made the decision that she wanted to put herself on to the organ donor register. So, in November 2018 Kathy went back to Lilly's home to talk to her about becoming an organ donor. Lilly herself signed onto the organ donor register that day.

In December 2018, Lilly went to Great Ormond Street Hospital for an appointment and it was found that her condition had improved enough that she was eventually listed for a heart and lung transplant. Now the wait had begun.

At 03:00hrs on the 26th March 2019 Lilly and her family received the call. A suitable organ donor had been found. The transplant operation went ahead with no complications. Lilly spent 8 weeks in Great Ormond Street Hospital recovering from her operation.

Lilly is now home in Llanelli and enjoying life as a regular 11-year-old, she is looking forward to her birthday in August.

Author

Bethan Moss, Team Manager – South Wales Organ Donation Team on behalf of the Kendall Family

Responsible Director

Anthony Clarkson – Director of Organ Donation and Transplantation