NHS
Blood and Transplant

Board Meeting in Public
Tuesday, 02 December 2025

Title of Paper	Patient Story – Rachel Easter	**Agenda No.**	2.1
Nature of Paper	☒ Official	☐ Official Sensitive	
Author(s)	Rachel Easter		
Lead Executive	Dee Thiruchelvam, Chief Nursing Officer		
Non-Executive Director Sponsor	N/A		
Presenter(s) at Meeting	Rachel Easter		
Presented for	☐ Approval ☐ Assurance	☒ Information ☐ Update	
Is there a plan to communicate this to the organisation?	☐ Yes	☒ No	☐ Yet to be determined

Executive Summary

Rachel has undergone a liver transplant, received blood, and had heart valve surgery involving both donor tissue and mechanical valves.

Previously Considered by

N/A

Recommendation

This is presented for information only

Risk(s) identified (Link to Board Assurance Framework Risks)

N/A

Strategic Objective(s) this paper relates to:

☐ Collaborate with partners
☐ Modernise our operations
☐ Invest in people and culture
☐ Grow and diversify our donor base
☐ Drive innovation

Appendices: N/A

My symptoms began when I was in my early 20's and at university in Plymouth. I was in my second year of my Psychology degree when I noticed that my skin was becoming increasingly itchy. It would start in the early evening and continue throughout the night.
I ignored it for a few months thinking it would go away on its own, until I got to the point where I would be scratching so much in the night that I would wake up with my legs sore and bleeding.

I was referred to Derriford hospital and had multiple blood and urine tests and a liver biopsy, but it wasn't until I was back at home in London that I got a diagnosis of Primary Sclerosing Cholangitis, a condition which affects the bile ducts in your liver.

I lived with the condition for a few years, going back and forth to the hospital, itching on and off but it wasn't until I was married and became pregnant with my first child that the condition worsened.
I had been told that the pregnancy might cause problems and as the months went on I found I got more and more itchy to the point where it was almost unbearable, but I was having regular tests and it seemed the baby was fine so I tolerated the itch until, at 28 weeks, my waters broke and 2 days later I went into labour. I gave birth to a baby boy, Charlie, who was just 1lb 14 oz. He went straight into intensive care at the Birmingham Women's hospital where he was well cared for and 3 months later, having had a blood transfusion and multiple operations, we brought him home.
We were delighted that he had come through it all and when I started to feel desperately tired, I just put it down to the sleepless nights and breastfeeding which seemed endless!
I became progressively weaker and after what I thought was a sickness bug I went into A & E where I was told I had developed esophageal varices, and I had been bleeding internally for possibly weeks. I had lost so much blood I was just hours away from a heart attack.
Thankfully I was given a blood transfusion, treatment for the varices began and I started to feel better. Treatment involved going to the hospital every 2 weeks to have an endoscopy and the veins banded until they stopped growing and fell off. This went on for months, but I was feeling much better and enjoying my time with my new baby.

However, my liver condition was worsening and when I went to the hospital to talk about having another baby, I was told that I would need a liver transplant before trying for another baby.
This was the first time I had been told that I needed a transplant, so my husband and I were understandably very shocked and desperately worried. We were asked to come for an assessment and told that without the transplant I had only two years to live.

Thanks to the amazing work of donor organisations and the liver team at the QE hospital, a donor liver was found and within 6 months I received the call and went into surgery. I remember waking up and my skin didn’t itch anymore and I wasn’t freezing cold. It was life changing.
Seven days later I came out of the hospital like a new person and a year after that I had my long-awaited second child, Oscar.

While I was in the hospital, I was given the opportunity to write to the family of my donor and thank them for what they had done. It was a hard letter to write as I was acutely aware that while my family celebrated new life, theirs grieved but I wanted them to know what they had done for me. They had given me the chance to see my child grow up and the possibility of giving him a brother or sister and for that I am and always will be truly grateful.

Unfortunately, my story doesn't end there. Seven years later and now with 3 children, Charlie 10, Oscar 6 and Emily 2, I got the shocking news that I needed two of my heart valves replaced.
I had started to feel breathless when walking and had been back and forth to A&E, when a scan showed that I had Shone's syndrome and needed both my aortic valve and my mitral valve replaced as they had become severely narrowed.

There was some concern about what to do as the valves were so small they were not sure that they could get new ones that would be suitable. Eventually the Birmingham Children’s

Hospital was contacted and a surgeon from the hospital was called upon to operate on my heart, one who was used to dealing with valves as small as mine.

I had the Ross procedure, where my pulmonary artery was replaced by a donor artery and used to replace my aortic valve and my mitral valve was replaced with a metal valve.

This time my recovery was not so quick, my right lung collapsed, and I was in hospital for 7 weeks, leaving my husband to manage our three young children.

I will never be able to thank all the teams that worked together to save my life enough. Without them I wouldn't be watching my children grow up. I have talked to my children about the importance of being a donor and I promote giving blood and being a donor whenever possible. I am now still happily married and back at work tutoring and supporting children with trauma and SEN. I am passionate about keeping myself healthy and I exercise and eat well. I feel privileged to have been given a second chance at life and I want to make sure I look after my body in the best way that I can.

Rachel and Charlie

Rachel and Charlie recently

The family