NHS Blood and Transplant

Board Meeting in Public

Tuesday, 29 September 2026

Title of Paper	Board Patient Story	**Agenda No.**	2.1
Nature of Paper	☒ Official	☐ Official Sensitive	
Author(s)	Susan Miller – Liver transplant recipient		
Lead Executive	Anthony Clarkson, Director of Organ and Tissue Donation and Transplantation		
Non-Executive Director Sponsor	N/A		
Presenter(s) at Meeting	Susan Miller		
Presented for	☐ Approval ☒ Information ☐ Assurance ☐ Update		
Is there a plan to communicate this to the organisation?	☐ Yes ☒ No ☐ Yet to be determined		

Executive Summary

Susan received a donor liver in 2025 and tells her story.

Previously Considered by

N/A

Recommendation

The Board is asked to note the Board Patient Story.

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

Strategic Objective(s) this paper relates to:

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

Appendices:

Before

I am a wedding and funeral celebrant. I stand at the front of the most significant days of other people's lives — their marriages, and their celebrations of life. Before I was ill I was an outdoors person: munro bagging, hill walking as often as I could be, I was extremely social with wonderful family and friends. I loved travelling and myself and my wonderful husband of 36 years, Robert, have shared a fantastic life.

In my thirties I found out I had polycystic kidney, liver and ovarian disease, a hereditary condition. The ovarian cysts caused me so many problems that in my late thirties I had a hysterectomy, which put me onto HRT far earlier than nature intended. It is now thought that this is what caused, or at least accelerated, the growth of the cysts on my liver.

Getting worse

The cysts grew. My liver swelled until I looked and felt eight months pregnant. My energy collapsed. I was in constant pain. The hills went first, then the ordinary things, and my quality of life deteriorated fast in my late 40's/early 50's.

After a few years of trying other options, I was put on the liver transplant list in June 2022. I know that being listed is frightening for a lot of people. For me it was the opposite. I was so grateful to be on that list. I had fought to be on it, It meant I had a future, and I had hope.

The wait

In October 2024 I got a call. I went in, and I tested positive for Covid. I was sent home. You wait for a phone call for more than two years, it finally comes, and then it doesn't.

The call, and the decision

The next call came on 3rd April 2025. The liver had been flown up from England overnight. They put it on the perfusion machine, and the team were not sure it was strong enough.

There were discussions. My surgeon sought advice from across the team, and then he came and sat with me and Robert and laid out the facts plainly:

- It is a below par liver.
- You are not at death's door.
- It is a risk to transplant it.

And then he asked me directly whether I wanted it, because I was the only person who could answer that question. It was my life at stake.

I asked him two questions.

What will happen if it doesn't work? You won't wake up.

And what will happen if it does work? You will wake up.

Honesty is always the best policy.

I had been waiting for nearly three years. My health was deteriorating. Nobody could tell me how long the next wait would be, or what condition I would be in by the end of it.

I said yes. It simply felt right.

I want this board to know how much that conversation mattered. He did not decide for me, and he did not dress it up. He gave me the truth and let me make my own choice. That is the single best piece of care I received, and I received a great deal of excellent care.

Surgery

I said my goodbyes to Robert and went down to the theatre. I woke up five days later in intensive care. There had been bleeding problems during the operation. They left me open for three days to let my body rest and seal some of the smaller leaks itself, then went back in and the fantastic surgeons completed my transplant. It was a hugely stressful time for my family. Thankfully, I slept through it!

I was stable enough to move to HDU two days later, and onto a ward two days after that. I am an extremely positive and determined person. I followed every physio and medical instruction to the letter. My body, unfortunately, was just as determined — I have a strong immune system, and my liver started to reject, twice. The amazing team at Edinburgh successfully managed it both times.

The ward

The first three weeks were harrowing and at times frightening. What got me through was my family, especially my sister who was by my side every single day, and the other three people in my ward, all of whom had had a liver transplant within a week of mine. We built a bond that I did not expect and could not have manufactured. We celebrated every win, collectively — staples out, medication reduced, first walk down the corridor etc. We are still in touch.

After I was discharged, I had some heart problems and had to go back in. Looking back, most of it was anxiety. I had been so well looked after that going home was genuinely frightening and daunting and full of, “but what if something goes wrong?”

I was regularly seen in the clinic and have never felt deserted, even now that is still the case. I simply can’t speak highly enough of all the team in Edinburgh, from the surgeons, all clinicians and the cleaners. I can’t fault any of them.

So, once I was home, I set goals to build up my fitness again. I started walking to one lamppost. Then two. Then the end of the street. And I continued to build up from there.

I didn't realise how bad I felt. The decline was so slow that I had just got used to it. Then I woke up from the operation and felt the difference straight away — and as I recovered, I was amazed every single day at how good I felt!

Writing to my donor's family

I asked to write to my donor's family. It is the most emotional letter I have ever written. Since then, I have been in regular contact with my donor's wife and daughter, and that relationship means a great deal to me.

Robert

In January 2026, nine months after my transplant, my husband and partner since we were 14 years old, Robert, died suddenly at home.

He had seen what a stranger's family had done for me, and he wanted to make sure his organs were donated when the time came. We both thought it would be a lot further down the line! When he died, I was told he could not be considered for organ donation, because he had died at home. I understood the reason. It was still very hard to be told that his wish could not be honoured, when I was only alive because someone else had.

So I have now been on both sides of it. I have been the person given my life back by a family who said yes at the worst moment of theirs, and I have been the family, told no.

Where I am now

I feel better than I have in years. I am back out hiking — not munros yet, but I am working on it. I am working as a celebrant again and I have built a business.

I also conduct funerals, which means I sit with grieving families at more or less the point in their lives where donation conversations happen.

I am grieving.

I feel so close to my donor’s family having suffered the same huge loss.

I am so grateful, there are no words.

It feels like one big circle.

However, My kidney function is now deteriorating, and I will meet the kidney transplant preparation team this autumn. I just hope I have some time between having to go onto Dialysis to be able to fit in travelling! I expect to join the Kidney transplant list within the next year. Honestly, I am not fazed. Having come through a liver transplant, and worse, the death of my Robert; dialysis and a kidney transplant look manageable.

What I would like to leave you with

I am grateful beyond words. I have my life back, and I have my vitality back with it — the energy, socialising with friends and family, the planned holidays, the hills, the work I love and my zest for life. Fate then dealt me a cruel turn. Robert died, and the future I had only just been given was swiped away from me. I am planning a different future. Still exciting, just different.

All I have been through recently has only made me even more determined to live my life to the fullest, every single day, because I know exactly what it has taken, from so many people, to get me here. And no way will I let anyone down, especially me!

Every evening I say goodnight to my Robert, and a thanks to Matt, my donor.
Every morning I say good morning to my new life and plan to make it as wonderful as it can be.