

Board Meeting in Public Tuesday, 26 November 2024

Title of Paper	Donor Family Experience	Agenda No.	2.1
Nature of Paper	<input checked="" type="checkbox"/> Official <input type="checkbox"/> Official Sensitive		
Author(s)	Judy Coutinho		
Lead Executive	Dee Thiruchelvam, Chief Nursing Officer Anthony Clarkson, Director of Organ Donation and Transplantation		
Non-Executive Director Sponsor	N/A		
Presenter(s) at Meeting	Judy Coutinho, mother of Alex		
Presented for (tick all that applies)	<input type="checkbox"/> Approval <input checked="" type="checkbox"/> Information* <input type="checkbox"/> Assurance <input type="checkbox"/> Update		
Executive Summary (max 300 word count)			
This board story is told by Judy whose son, Alex, died suddenly in January 2020. He donated his heart, lungs, liver and kidneys.			
Previously Considered by			
N/A			
Recommendation	This board story shares the story of a donor family. It is for information and to help inform improvements in our practice.		
Risk(s) identified (Link to Board Assurance Framework Risks)			
04 Donor Numbers and Diversity			
Strategic Objective(s) this paper relates to: [Click on all that apply]			
<input checked="" type="checkbox"/> Collaborate with partners <input type="checkbox"/> Invest in people and culture <input type="checkbox"/> Drive innovation			
<input checked="" type="checkbox"/> Modernise our operations <input checked="" type="checkbox"/> Grow and diversify our donor base			
Appendices:	See below		

NHSBT Board Meeting

November 2024

Status: Official

Judy Coutinho – Donor Family Experience

Son – Alex Newlove aged 27 years old.

Donated his heart, lungs, liver & kidneys.

Saving or changing the lives of 6 people.



My eldest son Alex died from a sudden catastrophic brain haemorrhage in early January 2020. We had no warning as he had never had any significant illness.

Alex was living and working in Chicago, Illinois. He had a glittering career with Grant Thornton and 'potential partner' had been suggested. He was popular, well-loved and had everything to live for.

He came home to spend Christmas & New Year with his family and friends. The day before he was due to fly home to the USA, my partner & I found him collapsed in his brother's apartment in Central Manchester. We were aware that he had felt unwell with a headache the day before, so we had gone to collect him. We heard him fall to the floor with a thud as we knocked on the door and we had to break in to reach him. It was obvious he wasn't breathing & my partner Gary started CPR as I hysterically called 999.

The police & ambulance arrived after what seemed an eternity and Alex was 'blue lighted' to Manchester Royal Infirmary. I travelled with him in the ambulance whilst Gary spoke with the police. We couldn't understand what was wrong.

At A&E, Alex was rushed into resuscitation while I made the phone calls to his father & 3 brothers to get to the hospital from Preston... 43 miles away.

I will never forget the A&E Consultant who told us that Alex had suffered a massive haemorrhage all around the brain stem and there was nothing that the neurosurgical team could do. I said 'I know what that means & Alex would want to be an organ donor'. I knew that my handsome, charismatic son would never breathe on his own again.

We were transferred to ICU to be looked after, and it was 24 hours later that he had the brain stem tests and was officially declared dead. It was difficult to take in as he was on life support, felt warm and appeared alive. I spent hours holding his hand and talking to him as 50 family & friends came from all over the UK to say goodbye.

We had to deal with the masses of questions and paperwork. The MASH questions were at times ridiculous and pointless. It isn't appropriate to ask the mother of her 27-year-old dead son when he last had unprotected sex! Some common sense needs to be applied when considering who is answering the questions.

Alex was eventually taken to the operating theatre at 3am on the Wednesday morning. I had been aware for the last 12 hours that the organ donation machine had started & calls were being made to centres all over the UK.

I would have welcomed having somebody dedicated to look after us... the donor family. It is incredibly frightening and lonely, especially when you are sleep deprived and in profound shock. The ICU & SNOD nurse were excellent but had so much to do.

Ten of us escorted Alex to the operating theatre doors. As the doors closed, we broke down. We knew the retrieval would take 8-10 hours. His father & 3 brothers slept on the floor in the ICU whilst my partner & I had a small room. I appreciated that the NHS has many constraints, but this isn't acceptable, and I feel more should be done to help donor families at the most tragic time. The adult services could learn a lot from paediatrics who give better care to the whole family.

Alex donated his heart to 19-year-old Chloe. She had an extra 3 years with her family before dying in February 2023. His lungs went to 14-year-old Lily who is now in her 1st year at university. His liver was split with the larger part going to a lady in her 50's and the smaller part to a little boy called Ted. He is doing well and his favourite subject at school is 'chatting to his friends'! Alex's kidneys went to a young lady in her early 20s who had been on dialysis for 6 weeks and to 28-year-old David who had been waiting for 2 years.

I support organ donation and whilst harrowing, it does bring some good from tragedy.

Author

Judy Coutinho

Responsible Directors

Anthony Clarkson, Director of Organ Donation and Transplantation

Dee Thiruchelvam, Chief Nursing Officer