NHS Blood and Transplant

NHSBT Board – Patient Story
Ava King
November 24th 2016


Ava King, now aged 7, underwent lifesaving heart surgery and received a cardiovascular graft from a deceased donor (allograft) at Great Ormond Street Hospital when she was ten days old. The surgery she had was aortic arch surgery, this is required when babies are born with problems involving their aortic arch – the first bit of the main blood vessel taking blood from the heart to the body. This is a rare congenital heart defect. In these circumstances babies like Ava are very ill, breathless, clammy and have difficulties feeding. Ava and her father Simon King visited Speke in January 2013 to share their story at the Tissue Services Annual Review Day. As well as the audience being greatly touched by the story, Ava won over everybody's hearts by walking amongst them, shaking hands and giving "High Fives". Although there are alternatives, like animal-derived grafts, cardiac surgeons specialising in congenital surgery prefer to use allografts as they provide better clinical outcomes. This is due to their similar properties to the patient's own tissue, which cannot be replicated by animal-sourced or prosthetic materials. Animal and bioprosthetic grafts are less pliable and do not integrate as well with the patient's tissue. Allografts also last longer and calcify less than these materials, meaning that the patients do not need to be re-operated on as frequently. However Ava may need repeat 're-do' surgery in the next few years as she grows up.

Heart valve grafts are size matched between the donor and the recipient. Maintaining a stock of appropriately sized allografts is a challenge not only for NHSBT, but for heart valve banks all around the world. NHSBT consents more than 95% of heart valves donated in the UK. Hearts for heart valves are donated mainly by organ donors (72%) or deceased tissue donors (24%). A small proportion (4%) come from domino hearts, where patients undergoing heart transplant donate their own hearts for banking of heart valves, or from deceased donors consented by non-NHSBT coordinators employed at hospitals. To help improve the provision of allografts to patients, NHSBT has established a 'National Fufillment System' (NFS) which is a centralised inventory management system for efficient stock management of heart valve allografts. It was set up to combine all the inventories across all the heart valve banks in the UK, to implement a transparent, consistent and equitable supply for all patients across the UK. The NFS model has been presented at European tissue banking conferences, and heart valve bankers from other countries have visited Liverpool to learn how the model

works. The NFS provides a single point of contact for surgeons, so they no longer need to contact multiple heart valve banks to determine what grafts are available. It also helps NHSBT understand the national clinical requirement for heart valves, so that we can develop our donation programs appropriately. For example, currently there is a gap between demand and availability for pulmonary grafts, particularly for medium sized valves. Heart valve grafts with this diameter are typically donated by children from the age of 2-18 years, and this knowledge helps us focus our efforts accordingly. This is challenging, as there are very few suitable donors within this age group. We will continue to raise awareness of the need for heart valves, particularly pulmonary and paediatric valves, through organ donation committees and media campaigns, to help patients like Ava King.