

Robbie Burns Cardiothoracic Transplant Advisory Group (CTAG) – Patient Group Chair



Robbie & Tamsin

Introduction

I was delighted to be offered the opportunity to become the new chair of the CTAG Patient Group. It will be a privilege to represent the views and interests of all heart and lung transplant patients (both before and after transplant) across the UK.

About Me

I underwent a heart transplant in June 2020 for end stage heart failure secondary to congenital heart disease, I was 49 at the time and had waited approx. 4 months on the urgent waiting list.

I am now 51 and live in Winchester with my wife, Tamsin. The decline in my health led to my early retirement, but before that my entire working life was in NHS hospital management. I have worked in several hospitals and finished my career in board level positions at Great Ormond Street Hospital. I have extensive experience in the management and development of cardiothoracic services including transplantation and hope my prior knowledge and experience will help me in this role.

Initial thoughts on the role

Going through a heart or lung transplant is physically and mentally challenging. The whole process is extremely hard, the illness leading to the listing decision, the decision to be listed, the waiting, the operation, the recovery and then the lifelong treatment regime. It takes our bodies and minds to their limits and frequently beyond.

There are approx. 5,000 of us in the UK and I want to ensure that our views and needs are heard, listened to, and acted upon in both the decisions being made about heart and lung transplant services and the day-to-day delivery of these services. I want to find ways to seek the views of as many of us as possible to ensure the most frequent challenges we face are the ones being addressed.

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