‘The Patient’s Voice’ within a national blood service

We organised a highly popular event entitled ‘The Patient's Voice’ at the NHS Blood and Transplant centre in Colindale, which brought together patients and healthcare professionals. The patients eloquently shared their perspective on living with sickle cell disease (SCD) and thalassaemia and the impact of transfusion on their lives, and the healthcare professionals working ‘behind the scene’ spoke about the ‘safe journey of blood’ and steps to improve the blood supply. This was followed by a lively discussion on how to better reach different ethnic minorities to encourage donation of rare blood units essential for these patients who develop red cell antibodies.

We also organised a linked event at Barts Health NHS Trust, where several patients with SCD gave emotional accounts on the impact of this disorder on their lives and the need for transfusion for stroke and renal transplant. Laboratory teams welcomed the opportunity to hear these stories and both groups were fascinated by an expert presentation on advances in patient care and ongoing research, including the potential for culturing red cells in vitro and gene therapy. Messages were shared by Twitter with a wider national audience and both events were supported by the Sickle Cell Society, UK.

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Michelle Martin                  Sally Proctor
Training Manager                  Scientific Consultant
Haematology and Blood Transfusion NHS Blood and Transplant
Barts Health NHS Trust

Dr Shubha Allard
Consultant Haematologist
Barts Health NHS Trust & NHS Blood and Transplant

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