NHS Blood and Transplant

NHSBT Board

Patient Story
Extracorporeal Photopheresis

26 January 2017

[REDACTED] was diagnosed with chronic myelomonocytic leukaemia at the age of [REDACTED]. The Filton Histocompatibility and Immunogenetics (H&I) laboratory performed tissue typing for both him and his sister, confirming a full match. He received intensive chemotherapy and a stem cell transplant at the Avon Haematology Unit in Bristol. His sister donated peripheral blood stem cells in the Therapeutic Apheresis Service (TAS) unit in Bristol and the transplant was processed by the Filton Cellular and Molecular Therapies laboratory.
Following the transplant, the H&I laboratory confirmed that nearly 100% of his circulating blood cells were from his donor within a month of the transplant. His leukaemia has been cured but he unfortunately he developed significant side effects three months post-transplant with abnormal liver function tests, skin and gut problems caused by chronic graft versus host disease (cGvHD). Initially he responded to first line treatment with steroids but these caused significant effects, namely cataracts and avascular necrosis of the hip leading to pain and poor mobility. The orthopaedic surgical team were not happy to proceed to hip replacement whilst [REDACTED] remained on high doses of steroids due to high rates of complications. Extracorporeal photopheresis (ECP) is recommended second line therapy in cGvHD.

He was therefore referred to NHSBT's unit for ECP. [REDACTED] has now been receiving ECP at the Bristol TAS unit for 15 months. He is one of 13 patients currently receiving this therapy there. Initially his treatment required procedures on two consecutive days every two weeks but after nine months this was reduced to two consecutive days every four weeks. Each procedure lasts 60-90 minutes. Needles are placed into veins in his arms and blood is drawn into the machine. During the first stage of the procedure, blood is spun to divide it into the constituent components allowing the white blood cells to be harvested. A chemical is added to the white blood cells that makes them sensitive to ultraviolet light and they subsequently die, changing the balance of the immune system and reducing the damage from cGvHD.

The therapy has worked well with no signs of cGVHD now. He has been able to progressively reduce the dose of steroids, which are planned to stop within the next month. The reduced steroid dose allowed the surgery for his cataract and a hip replacement to be performed and he is now significantly better and returning to a normal life. The ECP will be stopped in three to six months.

TAS is now directly commissioned by NHS England and NHS Wales to deliver ECP for cGVHD and cutaneous T cell lymphoma. This treatment is provided in the Bristol, Oxford, Manchester and Liverpool units. It is expected that NHS England and NHS Wales will also commission ECP for acute graft versus host disease during 2017 allowing treatment in a patient group for which there is no currently funded therapy.