NHSBT Board Meeting

A patient perspective: Intravenous Immunoglobulin

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Status – Official

This story is about Leanne Preedy, from Ongar in Essex, and her two children, who all rely on immunoglobulin made from plasma donation as they have a primary immunodeficiency called Common Variable Immune Disorder (CVID). Leanne has consented to her story being shared.

Common Variable Immune Disorder is a term used to refer to a group of deficiencies that vary in severity and symptoms, but which are all characterised by low levels of antibodies, part of the body's defence system for fighting off bacteria and viruses. People with CVID are at greater risk of all kinds of infections, some of which could become serious or even life-threatening. Intravenous immunoglobulin (IG) is the treatment of choice for patients with antibody deficiencies.

The clinical specialities using the largest amounts of IG are neurology, haematology, immunology, nephrology, rheumatology, and dermatology. Despite the increased supply of IG products in recent years, the demand has also increased simultaneously leading to an ongoing shortage of IG globally. NHSE has guidance on when to use IG and a demand management programme to approve the use in individual cases.

In the setting of the increased demand for IG, other factors that ordinarily might not impact availability may have a greater effect. These can include uneven product distribution across different localities, logistics of contractual obligations, production delays, and other factors. Health care providers, when faced with shortages of IG products, have taken steps to optimize limited supplies of IG for patients. These strategies have included lowering of doses, delay of treatments, prioritisation based on medical need, and use of alternative therapies where those exist. Equally, health care providers may also be required to decide which patients will receive priority treatment which could lead to disparity where evidence-based approach to such decisions is limited. These changes could have a negative impact on the clinical outcomes of some patients.

Leanne's story
Leanne was diagnosed aged 4, after a series of infections: *"I was very ill up to that age, I ended up with pneumonia and I was always very poorly and in hospital, with no diagnosis each time."* She has been receiving intravenous IG treatment for the last 29 years. Unfortunately, her two children also inherited the condition; they are under the care of Great Ormond Street, and they receive this medication twice weekly. It is unusual for three people in the same household to be all having this treatment. She still catches a lot of colds and illnesses but the immunoglobulin treatment she gets at home means that she has never been seriously ill. *"The infusions are very easy and comfortable thanks to amazing nurses who look after me,"* said Leanne.

Leanne receiving immunoglobulin therapy at home and, right, with her family

Leanne says of the restart of plasma collection in England ‘[it] *can only be a good thing and will help many more people have access to this treatment as many thousands of people rely on immunoglobulin to have a quality of life and be well/healthy and live their life to the fullest'*……*“I owe donors so much and ‘thank you’ will never ever be enough. I hope I can raise my children to be as kind and thoughtful as donors are.’’*…..“*Without immunoglobulin, life would be unliveable, quite frankly. ‘’*
“I wouldn't be able to be a mother, play with my children, teach them things, be their support, carer and mummy. I wouldn't be able to do simple things such as read and laugh with them. The thought of not showing them the world makes me sad. I don’t want to think about life without plasma donors and immunoglobulin.”

In the context of increasing demand and the impact on individuals, NHSBT is delighted to be able to restart the collection of plasma for fractionation/medicines for people like Leanne. For patients who do have their interval between doses extended or who are not able to access this treatment as often as they and their clinicians would wish, it can become extremely stressful. For clinicians, treatment decisions, whilst part of the job, can also be difficult.

Supply constraints globally mean that services worldwide are striving to build resilience by increasing the plasma collected and welcome the move by the UK. For NHSBT it is essential that we are able to meet our collection targets and increase our drive towards self-sufficiency for this critical medicine. We are also hoping that as UK plasma becomes risk assessed by regulators that more medicines will be able to be made from it. We were delighted with the recent decision by the Australian regulator to accept donors with a history of living in the UK for both blood and plasma

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