

Board Meeting in Public

Tuesday, 26 March 2024

Title of Report	Patient Story – Plasma for Medicine	Agenda No.	2.1
Nature of Report (tick one)	<input checked="" type="checkbox"/> Official	<input type="checkbox"/> Official Sensitive	
Author(s)	Donna Cullen – Head of Nursing, Plasma for Medicine		
Lead Executive	Denise Thiruchelvam, Chief Nursing Officer		
Non-Executive Director Sponsor (if applicable)	N/A		
Presented for (tick all that applies)	<input type="checkbox"/> Approval <input checked="" type="checkbox"/> Information <input type="checkbox"/> Assurance <input type="checkbox"/> Update		
Purpose of the report and key issues			
Purpose: Patient story, sharing their lived experiences of receiving plasma derived medicines for the treatment of life threatening and sometimes sudden onset of rare autoimmune disorders. The stories shared serve the purpose of keeping the NHSBT board connected to the life enhancing difference Plasma for Medicine (PfM) makes to patients.			
Previously Considered by			
PfM SLT have worked in collaboration with colleagues in Comms and Dx to ensure patient stories are representative of diseases treated with plasma derived medicines.			
Recommendation	The Board is asked to observe this session with an inquiring mind		
Risk(s) identified (Link to Board Assurance Framework Risks)			
Include Risk ID and Description – N/A			
Strategic Objective(s) this paper relates to: [Click on all that applies]			
<input checked="" type="checkbox"/> Collaborate with partners <input type="checkbox"/> Invest in people and culture <input type="checkbox"/> Drive innovation <input type="checkbox"/> Modernise our operations <input type="checkbox"/> Grow and diversify our donor base			
Appendices:			

1. Background

Plasma makes up around 55% of our total blood volume, and carries essential proteins, such as immunoglobulins, that help fight infections and diseases. When used as a treatment of rare and chronic autoimmune disorders, intravenous immunoglobulin (IVIg) helps to replace the lack of these critical proteins and normalise a compromised immune system.

This paper represents the stories of patients, who receive immunoglobulin therapies, for the treatment of complex and sometimes life-threatening rare diseases. It provides insight into the lived experience of those needing plasma for medicines and the life enhancing difference it makes every day.

2. Patient Stories

Emma Stone

Emma Stone said immunoglobulin medicine was 'like a miracle' after she began treatment for a rare disease.

Emma, aged 37, of Lower Earley in Reading, developed the rare autoimmune disease chronic inflammatory demyelinating polyneuropathy (CIPD).

Over around six months, she went from experiencing pins and needles in her hands, to often needing a wheelchair to leave the house.

Her immune system had begun attacking the nerves that send signals to her muscles.

Emma, a mum of two, said: "It was very scary, and it was very traumatic for my children to see. The treatment has given my kids their mum back again."

She started to notice weakness in her hands and legs in December 2020, followed by pins and needles. Her nerves became numb - she stopped being able to feel hot water.

By summer 2021, she could only walk small distances at home. Her limbs became almost paralysed. She often needed a wheelchair to go outside. Her mobility kept deteriorating through the year.

Emma, a beautician, said: "I basically couldn't do anything that required your arms or legs. I could not lift anything, I could not get in and out of the bath or even lift a drink or food to my mouth without a struggle, there was no way I could cut up my own food, dress myself or wash my own hair. "I tried to keep active. On better days, if my mum came and did my make up, and somebody drove me, I could just about sit in a chair out with friends."

CIPD is progressive. If it's not caught early, people can suffer permanent loss of mobility in their arms and legs, including the permanent need for a wheelchair, and the permanent loss of use of their arms.

"It was very frustrating and very scary. At first the doctors thought it was multiple sclerosis because a cousin has it. They also thought it could be caused by a rare cancer. They diagnosed CIPD with nerve conduction tests and a lumbar puncture. It was a relief at first that I had an answer to what was happening to me but then petrifying when I found out more, that it was incurable."

Emma was diagnosed in January 2022 and had intensive treatment with immunoglobulin soon afterwards.

Blood and Transplant

Immunoglobulin is a medicine made from the antibodies found in plasma donations. Emma said: "The initial treatment was the 'rescue treatment'".

"The effect was like a miracle. Within about four weeks it had made a huge difference and I could move almost normally again. It was amazing. However, there is a likelihood you will relapse without ongoing treatment. But my consultant had to present a case for me to get ongoing treatment because immunoglobulin is in high demand and it's very expensive".

"Thanks to my wonderful neurologist I was approved for ongoing intravenous immunoglobulin." Every three weeks, Emma now goes into Royal Berkshire Hospital to have three infusions of immunoglobulin over three days. Each infusion takes around four hours, and she receives around 25g of immunoglobulin during each infusion.

Emma said: "I am not 100% but I am pretty much 95%. Immunoglobulin has just changed my life completely. It's enabled me to work again, to be a mum again. It keeps stable so I won't dip again. It allows me to have my life back. I'd got quite depressed when I couldn't do normal stuff with my kids, like pushing them on a swing, picking them up when they fell, carrying them to bed and turning the pages on the book at night time story, my 7 year old was a life saver, helping care for me, helping me up when I fell and helping get his 4 year old brother ready for nursery, even doing their packed lunch with my guidance as my hands just didn't work".

"I've met quite a few other people at the hospital who said it has changed their life too.

"It's changing my life, giving me back my life as a mum and giving Vinnie back his life as a little boy and it's helping me live with having CIDP. I want to see it change so many more lives".

"Most people have never heard of plasma or immunoglobulin. Many of my friends have now donated plasma and they said they had no idea how easy it was to donate.

"I'd just say to all the wonderful people donating, thank you, you are giving my kids a mum back, and saving my family.

"It was very scary for my children when mummy relapses and ends up back in hospital but that changed forever thanks to this lifesaving medicine."

Gary Khan

Gary Khan went from fit and healthy to virtually bedbound and unable to walk after the sudden onset of an autoimmune disease.

The 56-year-old from Cookhill near Alcester developed chronic inflammatory demyelinating polyneuropathy (CIDP) - his immune system was attacking his nervous system, causing progressive weakness and impaired sensory function in the legs and arms.

Gary's condition continued to deteriorate until he received immunoglobulin, a medicine made from plasma, which led to his health being transformed literally overnight.

The former musician and former athlete turned coach and businessman started to notice symptoms in October 2020.

Blood and Transplant

“I got in the shower one morning and my toes and thumbs went numb, on both sides at the same time,” said the married dad of two.

He was diagnosed in early 2021 but despite treatment including steroids and plasma exchanges, his donation continued to deteriorate.

Gary said: “It would come back harder after each plasma treatment. By December 2021, between the CIPD and the muscle wastage, I couldn’t walk, I couldn’t dress or feed myself, or even hold a ben. I was essentially bedridden.”

His doctors at Queen Elizabeth Hospital Birmingham decided to try immunoglobulin, a medicine made from plasma. It contains healthy antibodies – part of the immune system - from plasma donors. These healthy antibodies help the recipient’s own immune system to calm down and stop the damaging attacks on the nervous system.

Gary said: “They told me there was only about a 60% success rate.

“I started a five-day course as an outpatient, going in daily. By day 4, I wasn’t feeling great. That evening, my wife and daughters had to tie a rope around me to help drag me up the stairs one by one. I woke up in the night, needing the bathroom, which my wife would normally have to do, but when I opened my eyes, my vision wasn’t blurry anymore. I could see one red dot on the telly, not three. My pain had reduced by half”.

“I stood up and I felt my power was back, given the muscle wastage. I walked to the bathroom in the pitch dark, washed my hands and went back to bed. The next morning my daughter came down to the kitchen to find her dad dressed and sat at the kitchen table. She took a video while she was crying of me skipping and jumping”.

“It was like someone had flicked on a switch and my muscles had begun to work properly again. I had joint issues and muscle wastage because of the condition but I have been doing rehab and now have very few problems.”

Today, Gary has infusions over two days every four weeks, which has kept him well. He is under the care of Yusuf A. Rajabally, Consultant Neurologist & Honorary Professor of Neurology.

Gary said: “Apart from a few niggles I have pretty much returned to normal functionality. I am really lucky. We found something that helped me, and I have been surrounded by people supporting me. I thought at one point that the best outcome would have just been able to stand up”.

“Until you’re a recipient, you don’t appreciate the importance of donating. Other than sporting injuries I have always been ill so this was a sobering experience. Plasma donation is invaluable. I applaud the people who don’t have a personal interest who just go and donate anyway. I think there are a lot of people who would donate if they were aware of it and knew more about it.”