

Status – Official

## NHSBT Board Meeting September 2018

## A Patient Story: Andy Colognori, Liver Transplant Recipient

I was first diagnosed with Cirrhosis of the Liver in January 2014 and started attending the Gastroenterology Dept of the New Victoria Hospital in Glasgow as an outpatient.

From the outset it was made clear that a liver transplant may become necessary if my liver continued to deteriorate. Having said that I found it difficult to believe that it would come to that. I attended consultations regularly over the next year with my condition being regularly monitored and a variety of further tests such as ultrasound, endoscopy and CT Scan being carried out. In February 2015 I was admitted to Glasgow Royal Infirmary suffering from extreme confusion and I was diagnosed with encephalopathy and was discharged 5 days later. The following month I was called for a further consultation in the Gastroenterology Dept of the New Victoria Hospital and was advised that we had reached a point where serious consideration would have to be given to a transplant. Following this my case was forwarded to the Scottish Transplant Unit for consideration.

In May 2015 I was again admitted to the Victoria Infirmary suffering from another bout of encephalopathy. Shortly afterwards, in July, I was admitted to the Transplant Unit for assessment. After five days of tests I was told that I had been accepted and would be placed on the liver transplant waiting list. Over the course of the next year I was re-admitted suffering from encephalopathy a further three occasions, October 2015, January 2016 and March 2016. On the second of these admissions I was taken from the QEUH Glasgow to the Transplant Unit in Edinburgh in the early hours as a potential liver had become available. After being prepared for the operation I was told that the surgeon had rejected the liver as being unsuitable for transplantation.

I was called through to the Transplant Unit again in March after a call to my home informed me that another liver had become available but again the operation was called off after the liver was assessed as being unsuitable. At this point in time I was acutely aware that my health was deteriorating and I was starting to run out of time.



In April I was visited at my home by a friend who I meet regularly for lunch with a group of other friends. He recently told me that he had circulated our friends warning them to expect bad news about me. Little wonder when I looked like this (see photo). I have to say that at this stage, particularly after two false starts, I felt pretty pessimistic about my chances of survival and had begun to put my affairs in order.

I eventually received another call from the Transplant Unit on the morning of 18 May 2016 and I travelled through to Edinburgh accompanied by my wife and son. After a tense wait we were briefed on the situation by Mr Powell the surgeon. He told us that there was a liver available that may be suitable but that there were risks attached to this specific liver as it was fattier than he was entirely happy with. He also told me that the liver was undergoing a period of reconditioning (something they called NRP). He explained what that did to the liver and that this was very new and therefore not a lot was known. He told me that he had numerous discussions with his colleagues about using this liver, even with NRP as the numbers were not guite perfect. He left us to consider the options. I had virtually made up my mind immediately as I felt that if I did not take the chance there was a strong possibility I would not survive long enough to be offered another liver. After a debate between the three of us we quickly came to the view that we should go ahead with the transplant. After telling Mr Powell of the decision a considerable period of time elapsed and I worried that the operation would be cancelled again.

I was eventually taken into the theatre at 6.00 pm on 18 May and came out at 4.30 the following morning. My wife and son travelled home while the operation was in progress but came back the following day and were present when I was taken off the ventilator on the afternoon.



After the operation I went through the usual recovery procedures moving from ICU to High Dependency and then to a ward. The actual recovery went smoothly if painfully and I received glowing reports from the team on ward rounds. My recovery was apparently textbook and the outcome justified this as this picture taken the day before my discharge shows

My health has continued to improve and the memories of how I felt before the transplant are just a memory. I am in no doubt that the NRP improvements made to the liver I received have made a huge difference to my quality of life and I will forever be in debt to the whole team at the Edinburgh Royal Infirmary Transplant Unit. I understand that it may have felt like I was taking a

chance at the time but it has certainly paid off. I am delighted if my experience leads to other patients getting the benefits of having the liver they are to receive enhanced by NRP.

I would be particularly pleased if my being a "guinea pig" leads to other potential transplants going ahead which may not be feasible without this procedure. I know what it feels like to wait seemingly interminably for a liver to become available. I am even more aware of the devastation felt when an operation is cancelled as the potential liver is rejected at the last minute. If the process of enhancing the liver reduces the instances of these experiences, it will be a major step forward.

My final thought is the query of whether one of the two transplants which did not go ahead could have done so if the reconditioning option had been available then. I would be delighted if the anguish of postponed transplants can be avoided for future patients.

## Author

Andy Colognori, Patient

## **Responsible Director**

Anthony Clarkson – Interim Director, Organ Donation and Transplantation