FIRST RESPONDERS
Lifeblood of the Emergency Services
Everyday He-Ro-es

Giving Evie and Heidi new life
Hello and welcome to the summer 2019 edition

Firstly, I’d like to introduce myself. I joined NHS Blood and Transplant in March and have spent the first few months travelling around the country meeting staff, donors and patients alike. Before I joined, someone told me I got the best job in the public sector. I know now how right they were. It is a joy and a privilege to work for an organisation that facilitates daily acts of altruism. It makes me emotional to look around a donor session and realise that the NHS runs on your selfless acts. On behalf of patients everywhere, thank you.

In this edition of our newsletter, we hear from the families of two little girls – Heidi and Evie – both with a rare and incurable blood disorder called Diamond-Blackfan anaemia (DBA) is a blood disorder that stops the body producing red cells. The lifelong condition is so rare that it only affects around 125 people in the UK.

Evie was diagnosed with DBA when she was just seven weeks old. Ever since then she’s needed blood transfusions every four weeks. She also has to carry an infusion pump to filter out the iron from her liver, and in some cases a stem cell transplant. Evie underwent a stem cell transplant in March.

Heidi has to go to hospital once a month for blood transfusions and treatment ranges from monthly blood transfusions to steroid therapy.

Heidi and Evie are two little girls with a rare blood disorder who rely on donors to stay alive which obviously interferes with normal life.

Evie’s mum, Rebecca, says, “Evie gets quite frustrated sometimes that she can’t do what her friends or her little sister can do, as often as she would like to. She does have a ‘rest day’ on a Tuesday where she is free to do whatever she can do, as often as she can. She’s seven now so asks a lot of questions about why she is different from Erin, her little sister, and she knows she has ‘special blood’.”

No cure
There is no cure for DBA, and treatment ranges from monthly blood transfusions to steroid therapy.
Special blood for babies

Why certain donors are in demand for poorly newborns

Similar to the virus that causes cold sores or chickenpox — in fact, around 50 to 60 percent of adults in the UK have had it. It can cause mild illness with symptoms similar to the ‘flu. It may also pass completely unnoticed with not a symptom in sight!

People are often infected in childhood but those in good health produce antibodies against it and make a full recovery. Once you have the virus, however, it stays in your body for the rest of your life, meaning that when we test your blood for antibodies to it, it shows up, even if you have had the illness years ago and have long since recovered.

The good news is that this is of no significance to your health. The not-so-good news is that it can cause life-threatening illnesses to patients with particularly poor immune systems.

Although CMV-positive blood is safe for most patients, it won’t be given to bone marrow recipients or newborn babies, for example. This means we have to give them blood from donors whom we know have never had CMV.

“CMV-negative blood saved my twins”

Born prematurely at 26 weeks, Rebecca Jewitt’s twin sons, Noah and Oliver, owe their lives to multiple blood transfusions of CMV-negative blood.

The boys each weighed around only two pounds (less than a kilogram) at birth and were both given transfusions within a week. Premature babies have immature bone marrow that cannot produce blood quickly enough and the boys also suffered from necrotising enterocolitis — death of bowel tissue — and so needed more blood during the surgery.

Rebecca says, “The constant cannulas being put in the boys was heart-aching to see, as their veins was so small and tiny they would collapse most of the time.”

She adds, “We could tell when they needed a transfusion, they would go really pale and lethargic. Immediately afterwards they looked fantastic!”

There were more infections, lung problems, bowel blockages and stomas but, after ten weeks, and more than 10 blood transfusions each, Noah and Oliver were finally discharged and able to come home.

Delighted to come home

They still have medical problems — for example Noah has had to have surgery for hernias — but the family were delighted they were able to be at home together, and the boys were no longer on oxygen.

Donors Janet Child and Ben Carter proudly give blood for neonates. Ben says, “Since becoming a father I’ve had a greater appreciation for what new parents go through in those first hours and days. If my donation can help with that, it’s the best thing I can do with my time.”

Rebecca says, “When they first said about blood transfusions, we were scared. But they had so many it just became the norm. You start to think ‘where does blood come from?’ People take it for granted that it will be there, but it’s only there because people donate. I don’t think people who donate blood understand just how much it is appreciated by the people who need it.

“The boys have both just turned four and are thriving. Without our wonderful NHS and blood donors, we wouldn’t have our boys and we forever live in their debt.”

Please remember, whether you have had CMV before or not, your donations still count towards saving and improving people’s lives. Thank you. You can find out more about CMV at www.nhs.uk/conditions/cytomegalovirus-cmv

I feel very proud"

Blood donor Mark Davies recently found out his vital donations were used for transfusing newborn babies.

He says, “I started giving blood in my early twenties and I’m 53 now. My father was a keen blood donor, giving over 60 pints in his time. He would often ask me to attend with him, but I would say, ‘Next time!’ or, ‘I’m too busy!’ One day I surprised him and gave it a try.

“My only fear was the needle. I remember thinking ‘This may hurt…’, but as I looked down from the bed the needle was already in my arm, with me not feeling a thing!

“Having fathered three children, I have a wonderful granddaughter and my daughter has recently mentioned another on the way, I feel flattered that my blood is used to help newborn babies. This was a surprise to me and I feel very proud.”

Proud to be NEO donors
Organ donation and you – BUSTING THE MYTHS

You may have heard that the law around organ donation is changing from spring 2020. If this is new information, don’t worry….read on!

It’s vital that everyone has correct and accurate information to enable them to make an informed choice about donating their organs after death. Here are some common questions we’ve been asked:

What is changing?
From spring 2020, all adults in England will be considered to have consented to be an organ donor when they die, unless they have recorded a decision not to donate or are in one of the excluded groups.

Who will be excluded from this?
People under 18, people who have lived in England for less than 12 months or who are not living here voluntarily, and people who lack the capacity to understand the change.

Why is the law changing?
Every day around three people in need of an organ die because not enough organs are available for transplant. The law is being changed to help save and improve more lives.

Am I losing control of what happens to my body?
No. It will still be for you to choose if you want to be an organ donor. If you decide that you don’t want to have your organs donated after your death, you can record this at www.organdonation.nhs.uk or by calling 0300 303 2094.

After spring 2020, will my family still be asked about donating my organs?
Yes. Your family will be involved before donation takes place, so it is really important that you discuss your decision with them so they can support your choice.

Will you consider my faith and beliefs?
Yes. Your faith and beliefs will always be taken into consideration before organ donation goes ahead. When you register as an organ donor on the NHS Organ Donor Register, you can now state whether or not you would like the NHS to speak to your family or religious leader before making a decision. Yes, it is OK to discuss your decision with the people who matter most to you.

Patrick’s Life Cycle

Patrick McIntosh likes a challenge and having cancer hasn’t stopped him doing some extraordinary feats

‘Lucky’ is not the first word that springs to mind to describe someone who has had three different kinds of cancer, but that’s precisely the term that Patrick McIntosh uses to label himself. He explains, “I gave blood in 2012 and tests found that my iron levels had fallen off a cliff. That led to me finding out, at the age of 58, that I had bowel cancer. Some might say I’m extremely unlucky but it’s quite the contrary – I’m incredibly lucky.”

Early diagnosis
Patrick believes he owes his survival to an early diagnosis; his low iron levels were caused by internal bleeding and surgeons operated almost immediately, removing stomach muscles, five lymph nodes, and over 40cm of his bowel. Although doctors had told Patrick that he shouldn’t have even been able to stand upright when he reported to hospital, just seven months later he was standing at the summit of Mount Kilimanjaro after a three-day climb.

But then there was more bad news. Patrick was diagnosed with prostate cancer and then skin cancer. His prostate, along with more muscles and further lymph nodes, were removed and Patrick still requires regular skin check-ups.

Challenge
None of this has stood in the way of Patrick’s thirst for a challenge, though. In 2015, whilst undergoing treatment for his prostate, he trekked to the South Pole to raise awareness of cancer, pulling a 45kg sled for 120 nautical miles in temperatures as low as -50°C.

As if that isn’t inspiring enough, the grandfather of two is now cycling from Twickenham Stadium to Tokyo in time for the Rugby World Cup this autumn. The ride will take him 7,000 miles across Northern Europe and Russia and he will make more than 50,000 metres of ascent. The money raised will be donated to St Catherine’s Hospice, West Sussex, and the World Cancer Research Fund.

“I’m doing this to raise awareness of how you can stay positive and increase your chances of beating cancer,” Patrick says, “and of course to raise money for great causes. Cancer affects so many people. A good friend of mine was diagnosed with bowel cancer at the same time as me.

“We were the same age, had the same level of fitness, the difference was I was diagnosed with stage 2 cancer, whereas he had stage 3 cancer. Sadly, my friend died a year after diagnosis. This made me even more determined to encourage people to get tested early and to change their diets and lifestyles.” We wish Patrick the best of luck on his ride.

To donate to Patrick McIntosh’s Life Cycle, a Global Ride to Fight Cancer, please search @kmgfoundation on social media or visit https://uk.virginmoneygiving.com/PatrickMcIntoshLifeCycle

BUSTING THE MYTHS

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"If you decide that you don’t want to have your organs..."
**Why Ro blood donors are in demand**

You may have heard the term ‘Ro’ being bandied about by us in recent years. ‘Ro’ refers to a very important subtype that just two per cent of our blood donors have. But demand for Ro blood is rising fast – increasing by 80 per cent over the last three years. To make sure that we can match supply with demand, we are turning up the heat with Ro donor recruitment, and for that we need your help too...

**Appeal for new black blood donors**

Ro blood is vital for treating patients with sickle cell disease. This inherited blood condition is on the rise in the UK, as the ethnic diversity of the population increases. Sickle cell disease disproportionately affects black people, and patients affected need regular blood transfusions, ideally with blood that is very closely matched to their own, which is most likely to be found within the same ethnic group.

Around 40 per cent of the black population will have this blood group, and so we are trying to recruit as many black blood donors as possible.

**Running in the family**

Ro blood is not confined to the black population, though: we are regularly contacted by Ro donors of other ethnicities who are surprised that they have this very special blood subtype!

Helen Day, one of our very own donor nurses at Cambridge Donor Centre, is herself an Ro blood donor. Helen says, “Even though I have worked for NHSBT for 20 years, I had not heard about the Ro subtype until I received a letter about three years ago informing me of my Ro subtype status. Naturally I was interested to find out more. Knowing that my blood helps patients with sickle cell disease is really important to me and I make sure I donate as often as I am allowed to.”

We often ask Ro donors to encourage family members to consider giving blood, too, as the chance of them sharing this blood subtype is far greater than for of an average person. Indeed, Helen’s son, Tom, also has the Ro subtype and says he is all the more keen to donate regularly.

“Some of my favourite programmes are ‘24 Hours in A&E’ and ‘An Hour to Save Your Life’. In them you can see when a patient is receiving a blood transfusion it’s not just one unit, it can be many. It emphasises how important it is that stock levels of blood are kept high. It makes me feel part of a bigger picture, donating blood. And since finding out I am Ro I am more committed to donating regularly.”

**The need is real**

Calvin Campbell, 55, from north London, was diagnosed with sickle cell disease at just six months old. He receives 10 units of blood every month through an exchange, where his blood is removed and replaced with donated blood.

Calvin has lived with varying degrees of chronic pain all his life and is never pain-free. Before joining the exchange programme, Calvin has lived with varying degrees of chronic pain all his life and is never pain-free. Before joining the exchange programme, Calvin, who sings in the B Positive Choir to promote blood donation, says, “More and more people are living with sickle cell and we depend on blood to give us our lives back. But there is not enough of the right blood to go round. I have had transfusions and exchanges postponed because of a lack of well-matched blood, and I have seen the impact on others of receiving blood that isn’t the ideal match. I don’t think enough black people understand the need to give blood or realise that people like me depend on donors of the same ethnic background. When people understand, they are willing to give.”

Calvin Campbell would like more black people to donate blood to help sickle cell patients like him.
Humans of Blood Donation

In 2018 we shared a story by the journalist and best-selling author Caitlin Moran about donating blood for the first time in almost 20 years. The scene she painted – one of “hot dust, floor polish and tea” and “love for someone you’ve never met” – resonated with many donors. In fact, there were so many positive responses in the days and weeks that followed, and so many donors replied with wonderful and heart-warming stories of their own, that we decided we ought to make it a regular feature.

“I drink my big glass of water, settle down to read my big newspaper, make sure I am familiar with what is about to happen, and the tiny risks involved. I consider what you are about to do, it is surely worth it. The team are great at talking you through everything as you go and answering any questions you have. My notes show that my blood is cleared for ‘neonatal’ use. It also means my single donation can help 12 babies. This is my fourth so far. Why? It doesn’t have antibodies that could harm small babies, either due to genetics or through not having been exposed to certain viruses. It is one of those late winter evenings that you would expect in the north west of England; cold, dark and damp. I will use my big northern coat for the 13-minute walk to Edgeley Park.

I go there a lot. Usually I am on my way to get a match ticket, or on match days and nights I am going to the ground. I go to watch our local heroes of Stockport County AFC. But tonight, as I cross Alexandra Park and turn right down Hardcastle Road there is no welcoming glow of the floodlights, no hubbub of fans arriving, of raffle ticket and programme sellers.

The ground is in darkness except for a welcoming glow from TNT Suite Number 2 under the Cheadle End, and the sense of anticipation is significantly different. As I enter I am greeted by the familiar sound of beeping machines and the welcoming efficiency of the Plymouth Grove team from NHS Blood and Transplant as they go about the important business of taking blood donations.

I register and the smile is warm but accompanied by the apology that they are running 40 minutes late. Would I like to cancel or rebook? But I take the responsibility, indeed the privilege of being a blood donor seriously, and so have booked for a time when I know I can be flexible, just in case. And the reason for the delay? The team plan for 20 per cent of the bookings not to show up, or maybe to delay? The team plan for 20 per cent of the bookings not to show up, or maybe to be unable to donate. But this is Stockport. Everyone is here.

I read again the instruction booklets to make sure I am familiar with what is about to happen, and the tiny risks involved. I drink my big glass of water, settle down to do emails, and start to prepare a Bible study for later in the week. In no time a friendly voice calls my name and we can begin. Identity details and medical history notes are checked. I fail the first haemoglobin test, but this happens and a retest is fine. We talk of football, the lady was also at Edgeley Park on Saturday: wasn’t the atmosphere fantastic? Do you think the Hatters will go up this year? With everything checked out we move on to the donor chair. I remark that for many years I was involved in the manufacture of blood bags for Baxter Fenwal, and we check the manufacturer of the bag that will take my blood.

My blood type is A negative, which means I could have been a universal platelet donor, but sadly my veins would not be up to it. My veins are proving a problem again, and for a moment I fear that we will not be able to proceed, but a detailed check shows the site we have used before. Yes, it does hurt just a bit as the needle goes in, but as you consider what you are about to do, it is surely worth it.

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If you have a way with words and want to share your story – be it about your first donation or your five hundredth – then please get in touch by emailing thedonor@nhsbt.nhs.uk, including your name and contact details.

“ar stockport.
Everyone is here”

Our first contributor is Steve Harrison from Cheshire.
Lifeblood of the Emergency Services

As an O negative donor, do you know just how important your blood is?

O negative is called the ‘universal’ blood type because it’s the only one that can be given to anyone in an emergency, which is why it’s carried by paramedics and air ambulances, ready to be used at accident scenes.

As an O negative blood donor, you are a part of the emergency services – a First Responder. Although you may not be with them at the scene of an accident, in the ambulance or at a busy Accident and Emergency unit, your blood will be. By the time an emergency happens, O negative donors have already provided their response by giving blood days earlier.

“Rushed into theatre”
Kirsty Armstrong received 16 units of O negative blood after suffering a massive bleed from a ruptured uterus.

She says, “I was in labour with my third child and given a syntocinon drip, but suffered a severe reaction which caused a tonic contraction, rupturing my uterus. It was the most excruciating thing I have ever experienced - I have never felt pain like it. My body went into hypovolemic shock and my blood pressure dropped so low I was struggling to stay conscious. “Luckily, my son Michael could be delivered by ventouse as his heart rate dropped. He was kept in the NICU and treated for oxygen deprivation and an infection, but thankfully is now a healthy 19-month-old.”

It was O negative blood that saved Kirsty’s life. During emergency surgery she received 16 units and four more whilst recovering.

Kirsty says, “I am so grateful to be alive. Thank you to everyone who donates blood. I am incredibly grateful for this generosity - without it I wouldn’t be here.”

“I nearly died!”
Back in 2017, shortly after the birth of her third daughter, Paula Taylor unknowingly developed an infection in her uterus, which in turn had ruptured a blood vessel.

She says, “I was bleeding internally heavily and still debated whether or not I needed to call 999 for an ambulance! I left my two beautiful big girls, Alice and Ellie, in the safe hands of my brother at home and my newborn baby in the arms of my distressed husband, Neil, and was blue lighted to hospital where I was rushed straight into theatre.

That night I underwent hours of surgery to try to save my life. The first procedure was meant to stop the bleeding, however it was unsuccessful due to the level of infection and the damage that had been caused. I was rushed back to theatre for an emergency hysterectomy almost as soon as I was wheeled into recovery; it was the only option to save my life.

“I was told afterwards that it was touch and go. The very talented team of experts who were saving me worked hard all night and I was very lucky to survive.”

The growing need for O neg blood

O negative donors are often called ‘universal donors’ because anyone can receive the red blood cells from their donations. This makes it vitally important in an emergency or when a patient’s blood type is unknown.

Although about 7% of the population has O negative blood, it accounts for around 13% of hospital requests for red blood cells.

Mike Stredder, NHSBT’s director of blood donation, says, “We need an ever growing share of our blood donors to be O negative to meet hospital demand. If you are O negative, please talk to your family and share your story. There’s a one in three chance they are O negative too. They will find out after their first donation.”

Thank you to everyone who donates blood. I am incredibly grateful for this generosity - without it I wouldn’t be here.”

“Without life-saving donors I wouldn’t be here today to see my beautiful girls grow up”
Marilyn’s daughter, Alice Fowler, was diagnosed with leukaemia in February 2016. She died in April 2018 on her 27th birthday. During the two-and-a-half years of treatment, Alice received 144 blood transfusions. It was these transfusions that improved Alice’s quality of life, allowing her to see friends and enjoy her time at home in between chemotherapy sessions.

Marilyn says, “She had a break at home for two weeks after the intensive treatment, thanks mainly to blood donations to get her back on top of things. The chemo was amazingly intensive. The first round of treatment, she had chemo twice a day for 10 days. It was really, really aggressive and it killed all of her healthy cells.

“She had to have blood donations when she became anaemic. She became short of breath and she became very lethargic. She had a bag of blood to improve the symptoms until her own body could then increase these cells to a level enough for her to go home, and for those two weeks she lived life completely to the full, completely.

“She was out and about with friends. I can’t tell you what she didn’t do - she made the most of those two weeks because she was back to normal health.”

New donors needed
Marilyn is helping to spread the word about the importance of new, young donors coming forward. Every year, we need 200,000 new donors to replace those who can no longer donate. Over half of current donors are over the age of 45, and we need to shift the balance to ensure future supplies.

“Blood donations let my daughter live life to the full”

A mother’s story

“A without life-saving donors I wouldn’t be here today to see my beautiful girls grow up. My newborn baby would have never known who I was. My husband would be on his own quite literally holding the baby! It’s unimaginable. There will never be enough ‘thank yous’ for what blood donors did for me that fateful night. From the bottom of my heart I am eternally grateful, and I know that my family are too.”

Emotional meeting
When Sebastian Cockerill was born by emergency caesarean section at 25 weeks his bone marrow was not mature enough to produce enough red blood cells to keep him alive so he needed several life-saving blood transfusions. One of these was from O negative blood donor Andrew Spence. Seb, now six, and mum Helen, recently met up with Andrew and Seb gave Andrew a special letter to say thank you.

Andrew started donating through work and has given blood more than 30 times. He says, “The day was fantastic - what an amazing emotional experience. Seb and Helen were wonderful. He truly is a remarkable young man.”
The Donor Crossword

Complete the crossword. The tinted squares spell out a component of blood. Send this name on a postcard or in a letter together with your name, address and daytime phone number to: Crossword Competition, The Editor, The Donor, NHS Blood and Transplant, 14 Estuary Banks, The Estuary Commerce Park, Speke, Liverpool, L24 8RB. You can also email your answer to thedonor@nhsbt.nhs.uk. You could win an NHS Blood and Transplant prize. Answers and the winner’s name will be in the next issue. All entries must be received by August 31st 2019.

ACROSS
6 Relish (6)
7 One of the Great Lakes (4)
9 Mature (4)
10 Type of piano (7)
11 Centre (6)
12 Append (5)
14 Stratum (5)
15 Small restaurant (6)
16 Dishevelled (7)
19 Ditch around castle (4)
20 Structure in eye (4)
21 English admiral (6)

DOWN
1 Provision (8)
2 Bullfighter (8)
3 Game bird (6)
4 Prophet (4)
5 Male ruler (4)
8 Mythological river (4)
12 Gathering (8)
13 Storyteller (8)
14 Praise (4)
15 Study of plants (6)
17 Scottish church (4)
18 Military dining room (4)

WE HAVE A WINNER!

Congratulations to Mr Michael O’Shea from Wembley in Middlesex who successfully solved last issue’s crossword.
The solution was: AB NEGATIVE