



Welcome to the new edition of the NHSBT Newsletter

Ian Trenholm

Our new Chief Executive says hello

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Help! I'm allergic to water!

It took nearly ten years for doctors to diagnose Nikki Clouden's rare autoimmune disease. Now, 20 years on, Nikki is dependent on plasma exchanges to make her life more bearable.

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Organ donation - A mother's story

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Every donation you make really does count, so it is only right that we recognise your contributions. In 2013 we carried out a full review of the programme and made some improvements.

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Blood donor Colin Waite explains how he became a platelet donor and how platelet donation differs from blood donation.

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Blood donation. Online and on target

We know time is precious for our donors so we are striving to make our online service as efficient and easy to use as possible.

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IAN TRENHOLM - AN INTRODUCTION

Hello and Thank You

I would like to take this opportunity to welcome you to the Winter 2014 issue of The Donor magazine and to introduce myself. I'm Ian Trenholm, the new Chief Executive of NHS Blood and Transplant.

I'm delighted to have joined the organisation and have been overwhelmed by the fantastic generosity of donors I've met during my visits to sessions.

It's become very clear to me already that you belong, as blood donors, to the world's greatest team. And that's why the theme of this year's National Blood Week was "Greatest Team in the World".

We now turn our focus to the winter months as this is traditionally a time when blood stocks dip. People can get distracted in the run up to Christmas and forget to get around to donating blood. So I'd ask you to donate if you can and not forget about your appointment. Last year, 1 in 5 blood donor appointments were missed around the festive season putting our operations under unnecessary pressure. We work very hard to ensure that hospitals get the blood and platelets they need every day and we can only do this with your support.

Throughout the winter colds and the flu can be rife, so it's worth checking whether you can still donate before coming to a session. You can look easily online on our website.

As we come to the end of another year, I would like to thank you all for your dedication to blood and platelet donation and I wish you health and happiness for the upcoming year.

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PLASMA EXCHANGE

"Help, I'm allergic to water!"

How donated plasma is helping Nikki Clouden cope with a rare condition

It took nearly ten years for doctors to diagnose Nikki Clouden's rare autoimmune disease. Now, 20 years on, Nikki is dependant on plasma exchanges to make her life more bearable.

"I suffer from aquagenic pruritus and aquagenic urticaria—which simply means I am allergic to water," says Nikki.

"If water touches me, if I drink water, if I get sweaty or if the air is humid it will trigger off a bad reaction. As you can imagine, it affects everything I do. Just think about how many times you come into contact with water on a daily basis. It's really hard. I can't keep fit as the reaction I have to sweating is so painful. Raising my daughter was a huge struggle. In the early years, I was able to wash dishes and do other household chores as the reactions weren't too bad, but now, even that is out of the question. My skin is now so sensitive that even the friction caused by getting dressed or cold air on my skin can bring out a reaction."



How it began

"I was around 26 years old when I first started getting the symptoms," recalls Nikki. "I found that my skin was stinging at different times. This stinging soon became more of an extremely painful burning sensation. It felt like millions of needles being stuck into me. It was painful. So painful that at times I would be crying hysterically because I just couldn't cope with it."

Nikki was baffled by her symptoms and understandably desperate to find the cause. "As I'd recently moved house I began to think that I was allergic to the carpet. Once I realised it wasn't that, I looked at other allergies that I might have. I began to see a dermatologist in Windsor and during this time we were able to discount perfumes and lotions. It was then that I began to think that water was causing the painful reactions I was having."

In 2005 Nikki was referred to a specialist in London who thought her symptoms matched those of aquagenic pruritus and aquagenic urticaria.

Rare disease

"The disease is so rare that when I was diagnosed there were only around three other people in Europe with the condition. I was initially treated with antihistamines, UVB radiation and a number of other drugs, none of which provided any type of long term relief. In 2007 after another 20-week bout of UVB radiation, the specialist decided that I should try a plasma exchange (see box)." Plasma contains the body's antibodies which make up the immune system. The specialist thought that Nikki's immune system was attaching

her own skin by responding inappropriately to water, so by removing the antibodies from her system, the response would be damped down.

Plasma exchange

A plasma exchange is exactly what it sounds like. Nikki sits down for a few hours and is hooked up to a machine which removes her plasma and then replaces it with albumin made from donated plasma.

"I usually spend a whole morning attached to the blood cell separator and the process can sometimes make me feel tired up to three days afterwards, she says.

"I have been coming to the therapeutic apheresis services unit at the John Radcliffe hospital for around seven years. At first I was coming twice a week but now, after carefully tracking my symptoms and how I feel after each treatment, I have been able to reduce my visits to once every five weeks.

"The staff at the centre always make me feel so comfortable and welcome. In the past seven years I have built up some great relationships with them. I even designed a wedding cake for one of the nurses."

The plasma exchange treatment hasn't cured Nikki but it does help to minimise her symptoms. "Once I have the exchange, the reactions I get are not as strong because it takes a little while for the antibodies in my blood to build up again. I'm not sure how long I will have to keep coming here but I do know that my life would be completely different if it wasn't for blood donors and the team."

What is a plasma exchange?

Blood is made up of red cells, white cells and platelets which are carried around in a fluid called plasma. The plasma can be separated from the other blood components, removed and replaced and this is a plasma exchange.

Plasma can be replaced with either fresh donated plasma or human albumin solution obtained by processing fresh plasma.

Plasma carries blood cells and various antibodies, hormones and proteins around the body. A plasma exchange is normally carried out when there is a problem caused by abnormal antibodies or proteins circulating in the plasma and attacking healthy cells.

A plasma exchange may improve symptoms but will not normally cure conditions because it does not switch off the production of the harmful antibodies.

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ORGAN DONATION

A mother's story

When her 16-year-old son was involved in a fatal road accident near their home on the Isle of Man, Diane Taylor agreed to donate his organs. This is her story



Diane Taylor's life was changed forever when her son, Daniel, died after a traffic accident seven years ago.

"Daniel was a normal, healthy, happy and very cheeky teenager. He did everything that a boy of his age would do," she says. "The day of the accident was a Sunday. Daniel, his brother James and James' girlfriend all came for a roast at tea time then Daniel decided to go back to his dad's house which was around 10 minutes from us.

"When I got the call from James (about the accident), I raced to the scene. I ran down the road and hugged James and his girlfriend. I then watched as Daniel was put on a stretcher. I was not allowed near him and could only watch as he was trying to sit up and was sick - a sign of a massive head injury. Daniel was stabilised at the scene for what seemed ages. I was not able to go in the ambulance with him - because of his injury he was being quite violent and he had to be sedated."

Intensive care

When Diane and Daniel's father reached the hospital, they were taken into a side room and given tea.

"Looking back I can see now how bad it must have been but at that point all I thought was that my son was being treated and he would be made well again. He was being kept unconscious to help stabilise him. The doctor explained that the X-rays showed no other injuries apart from the bang on the side of his head. We were encouraged to let him know

we were there as he would still be able to hear us. I'm so thankful that we were told this as those words from us were possibly the last he would hear from his mum and dad.

"We were told he was to be taken for a scan and then to the intensive care unit (ICU). His dad and I were then taken upstairs by a lovely nurse who was not only explaining the ICU but was also looking after us. My legs just seemed to buckle on the walk up there as the shock set in. A senior doctor explained how serious Daniel's condition was and that he would have to be flown to the mainland for specialist care. I remember hearing him saying he was critical but Daniel was my son and in my head that meant he would be ok."

Diane recalls seeing Daniel before he was taken away. "My beautiful son (was) covered in tubes but his only visible injury was a black eye. Again, the nurses encouraged us to touch and talk to him - I was so overwhelmed by it all that without them saying it I would not have touched him. As we left the hospital, I watched as Daniel was put into the ambulance to go to the airport."

Diane and Daniel's father caught the first flight out and were with Daniel by 9am the following morning. "I remember thinking how cold he felt and I wanted to cover him up. Throughout the day we were updated regularly. Always with us was another nurse or maybe even two. Looking back, I realise that we were being prepared for the worst. I did not or could not believe any of this was happening and just wanted him to wake up," says Diane.

Worst news

In the afternoon came the very worst news. "The consultant came in and actually knelt down on the floor in front of me. He asked me if I understood how serious Daniel's condition was. The consultant was so lovely and took my hand. He said that if Daniel's heart stopped now they would not be resuscitating him. His words were a shock but I will never forget how kind he was and the way he said it. After this a small incision was made in Daniel's head and a device was put in to show if there was any brain activity. Late afternoon, we were told that nothing more could be done for Daniel. At this point we were asked about organ donation. All I remember was saying yes."

The next step was talking with nurses from the organ donation team. "I remember them as being kind. The conversation and decision on which organs to donate was not an awkward one. Organ donation was never something we had ever talked about but without even having the conversation, his dad and I knew that Daniel would have wanted to help others."

Daniel was pronounced brain dead in the early hours of the morning. His organs were retrieved and he was able to help four people; his heart and valves were used for medical science. The organ donation specialist nurses told Diane that they would be with him in theatre and afterwards. "These two ladies gained my trust in such a short time and I knew that Daniel would be well looked after."

Diane says that donating Daniel's organs has helped her because something positive has come out of her terrible loss. "I hope that telling his and my story will help people see how important donation is not just for the recipients but also for the grieving family. I look back to the consultant who asked us and I'm just so grateful he did. His words, "Have you thought about organ donation" were not harsh - it is the reality of what can happen following a loss."

To find out more about organ donation and joining the organ donor register, visit www.organdonation.nhs.uk

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DONOR RECOGNITION SCHEME

Every donation counts

Take a look at our new donor recognition scheme

Every donation you make really does count, so it is only right that we recognise your contributions. We launched our original donor awards programme in 2002 and nothing much changed for several years, but in 2013 we carried out a full review of the programme to ensure it was still doing the best job of showing how much we appreciate your efforts. We knew we had to get it right and consulted widely with donors over many months.

"We always want our donors to feel appreciated for what they do," said NHSBT's Victoria Hatcher. "Our review included in-depth feedback from both donors and staff. The majority felt that the system was difficult to understand and that our gifts were old-fashioned."



A new ethos

Out of the research came a new approach that thanks donors for every single donation made. The new scheme awards credits rather than simply recognising the number of donations made. Victoria explained, "Credits are based on the quantity donated by a donor. For example, one unit of whole blood equates to one credit, whereas a triple component donation equates to three credits."

Giving credits

So what difference are donors now seeing? Victoria said, "Following every donation donors receive an email or text message thanking them for that donation. If they have reached a milestone a pack is sent to their home filled with personalised recognition gifts (see box for details)."

As well as the gift pack, milestones are automatically highlighted on donor health checks to make it easy for staff on session to see when someone is reaching a milestone with that day's donation. And, as a result of feedback, all session teams have been given thank you cards that can be easily personalised by staff to give to donors.

When you reach your whole blood century of 100 credits you'll receive an invitation to a special ceremony to be presented with a medal and a certificate. Component donors will be invited at 250 credits. There will also be events at donor centres to thank donors who have gone the extra mile and donated platelets.

We know donors are modest and you do what you do with no expectations of reward. Yet it is very important to us that we as an organization do recognise and celebrate your absolutely vital contribution towards the nation's health.

Said NHSBT's Jon Latham, "We are delighted with the new scheme and hope our donors welcome its value with each and every donation."

Credit milestones and what you will receive:

- 1st donation – Welcome and thank you pack (includes red plastic donorcard and key fob)
- 5th – Bronze plastic donor card
- 10th – Badge and mounted certificate
- 25th – Silver plastic donor card, badge and mounted certificate
- 50th – Badge, gold plastic donor card and mounted certificate
- 75th – Badge and mounted certificate
- 100th – Ceremony invitation (whole blood donors), Commemorative medal and framed certificate
- 150th – Mounted certificate
- 250th – Ceremony invitation (platelet donors), commemorative award and mounted Certificate
- 500th – Special framed certificate
- 750th – Special framed certificate
- 1,000th – Special framed certificate

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ASK THE DOCTOR

Why we ask you to drink water before donating

Our Nurse, Jane Pearson, answers questions about drinking water before donation.



Q Why am I asked to drink such a large amount of water just before I donate?

A When you donate blood, you give approximately 470 ml of blood, which is about 10 –13 per cent of your circulating blood volume. The actual percentage varies according to things like your gender, height and, most importantly, body weight. A loss in blood volume can cause a drop in blood pressure, which may make you feel dizzy or sick and even lead to fainting. Drinking lots of water (500 ml – about two large glasses) just before you give blood can help prevent this.

Q How does drinking water help?

A A study in the USA in 2004 showed that 500 ml of water drunk in no more than five minutes, 20 – 30 minutes before donation, creates a temporary increase in blood pressure. This can counteract the drop in blood pressure during donation.

Q How can water raise my blood pressure?

A There is a sort of chain reaction. As the 500 ml of water quickly fills the stomach it stretches and the peripheral blood vessels around the stomach constrict. To travel through smaller vessels, the blood has to be pumped harder by the heart, which makes blood pressure rise. In addition the fluid then moves from the stomach to the tissues where the body uses it to regulate itself against the sudden loss of 470 ml of blood.

Q What else do you do to make donating blood easier for donors?

A We are careful to only invite donors with a minimum weight of 50kg (7st 12lb). This ensures a donation will never remove more than 13 per cent of their blood volume. And our new style of donor chairs, put you into a recumbent position helping prevent blood pooling in the lower limbs, which can cause a drop in blood pressure (orthostatic hypotension). When you have finished donating, but while you are still sitting on the chair, we sit you up gradually, in two stages, to give your body time to adjust its blood pressure. This helps to prevent any feelings of faintness or dizziness.

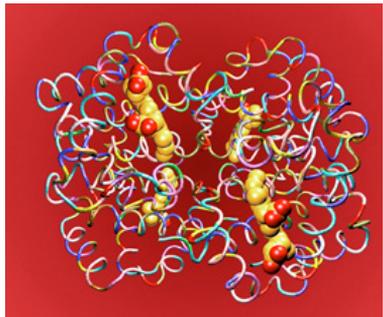
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SCIENCE AND TECHNOLOGY

A donor's guide to haemoglobin

What is it is, how it works, and why your levels matter

Your blood is red because of haemoglobin. This special molecule is a type of protein found in every red blood cell in your body. Each one contains about 270 million molecules of haemoglobin and each molecule can bind with up to four oxygen molecules – the crucial element your body relies on to survive. In the lungs, oxygen attaches to the haem part of the haemoglobin molecule and is then taken by the body's circulatory system to the tissues and organs where cells use the oxygen to release energy.



Red blood cells are made in bones that contain bone marrow mainly in the pelvis and long bones but also the ribs, vertebrae, sternum and cranium. If not enough red blood cells are produced, or they do not contain enough haemoglobin to bind with oxygen, anaemia may develop. This means the body can't supply enough oxygen to its tissues, causing symptoms like severe tiredness. One of the causes of anaemia can be low iron levels, which affects the production of haemoglobin.

Iron and haemoglobin

Human haemoglobin is a complicated molecule consisting of four major units, each containing a smaller 'haem' group. This group contains a single iron atom, held in the centre of a square made up of four nitrogen atoms, and exists at the heart of an array of organic rings called a porphyrin. It is this iron that binds oxygen and enables haemoglobin to do its job. And it's the porphyrin that gives blood its red colour.

Haemoglobin

Most people have 4 to 5 grams of iron in their bodies. Of this, up to 2.5 g is contained in haemoglobin and most of the rest (approximately 2 grams in adult men, and somewhat less in women of childbearing age) is stored as ferritin, the major iron storage protein of the body. Ferritin complexes are present in all cells, but are most common in bone marrow, liver and spleen. The liver's stores of ferritin are the body's primary source of reserve iron. In blood donors stores of iron tend to be slightly lower.

Each day approximately 1mg of iron can be absorbed from food as long as the diet contains sufficient iron in it (see box). However, most of the body's iron comes from recycling.

Red cells

Every day we use about 20mg of iron to make new red cells to replace the old worn out cells. During its approximately four-month lifespan, the human red blood cell travels around 300 miles, making about 170,000 circuits through the heart. Cells get damaged on these repeated journeys, which is why the body breaks them down and replaces them regularly.

Your iron levels

When you give blood it's important you have enough iron stores to be able to make up what you lose when you donate. That's why we test your blood every time you come to a session. Your haemoglobin levels will naturally change throughout the year, so don't be discouraged if your levels are too low to donate at one session. By the next time you come, they may have completely recovered and you'll be able to donate.

Boost your haemoglobin levels

Everyone needs iron in their diet to maintain healthy levels of haemoglobin. Keep up your levels by eating three portions of food containing iron every day.

All the following are good sources of iron:

- Lean red meat, turkey and chicken
- Liver
- Fish, particularly oily fish which can be frozen or canned (such as mackerel, sardines or pilchards)
- Eggs
- Breakfast cereals - some cereals have been fortified with iron
- Pulses and beans - in particular canned baked beans, chickpeas and lentils
- Nuts (including peanut butter) and seeds
- Brown rice
- Tofu
- Bread, especially wholemeal or brown bread
- Leafy green vegetables, especially curly kale, watercress and broccoli
- Dried fruits – in particular dried apricots, raisins and prunes



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PATIENT DONOR STORY

'My chance to help save more lives!'



Blood donor Colin Waite explains how he became a platelet donor

"It was 16 years ago when I saw an advert about the need for platelet donors. I had given my first whole blood donation at the age of 18 and after six donations I decided to swap to platelet donations," says Colin Waite, who lives in Bristol.

Platelets help the blood to clot, and are given to many different kinds of patients (see box). Colin's A- blood group is rare and special, because as the universal platelet type, it can be given to patients with any other blood group but as platelets have just a seven-day shelf life, donors like Colin are always needed.

Convenient to donate

"The first step started at the blood session I attended," he says. " Along with the routine blood samples another sample was taken to measure my platelet count to make sure it was high enough, plus they checked my veins to assess the suitability for donation on the cell-separator machine."

Colin got the green light and now donates as often as he can at our Bristol Donor Centre. "I currently work shifts so find I have the time to give platelets on my days off. It's very convenient for my life style."

As a platelet donor you can expect spend up to 90 minutes donating on a cell separator.

Donors can watch TV and DVDs, read, make calls from their mobile phone and use their laptop with free wifi.

Colin says, "I bring a book and my computer to help pass the time but often I just chat to the nurses. I find staff at the sessions very friendly; you get to know their names and faces when you visit them so often, they look after you throughout and keep you topped up with refreshments!"



What happens?

He now takes platelet donation in his stride. "It's like giving blood – the booking-in and confidential health check are the same. The only difference is that I cannot give platelets if I have taken aspirin in the last five days or an NSAID (non-steroidal anti-inflammatory drug), such as Nurofen, in the last 48 hours. The staff always monitor how I am feeling so they can adjust the settings on the cell separator machine if required. I know when my donation has finished because the machine beeps. Then the needle comes out and it's all over."

Says Colin, "Giving blood doesn't cost anything and I feel that by donating I can give something back to the community. There are a small number of ethnic donors and I'm proud to be one of them."

Typically, a platelet donor would expect to donate enough platelets for three adults or 12 infants.

Phoebe underwent two bone marrow transplants

Adrian and Lynn lost their first daughter Eleanor to a rare and fatal blood disease. Their second daughter, Phoebe, was saved from the same condition after undergoing two bone marrow transplants.

Adrian says, "It was so humbling to see the numerous, essential bags of blood and platelets given to Phoebe to keep her alive in the first few weeks after her chemotherapy, especially as they were "gifts of life" from people unknown to us."

Could you be a platelet donor?

Many donors move on to giving platelets from blood donation but you do not have to have been a blood donor first. If you have not donated before, you can become a platelet donor if you are generally in good health and aged 17 to 65. If you are over 65 and have given blood before you can donate platelets and if you are over 70 and have given a full donation in the last two years you are also eligible.

We need a short assessment to see if your veins are suitable, and also check your height and weight to see if you have a large enough blood volume to give two transfusions of platelets per donation.

Then you need to give a small sample of blood to determine if you have a high enough platelet count - about half the people tested do.

Your sample is assessed which takes about a week, longer for female donors as we have to check for antibodies associated with pregnancies. If all is well, we will get in touch and book you in for your first life-saving platelet donation appointment.

Donations take place at our 23 donor centres. You need to be able to spare up to two hours for the donation and health screening process.

You can donate platelets much more frequently than blood, up to 24 times per year, although we will welcome you as often as you can manage.

PLEASE ACT NOW

It is easy to take the first step to saving even more lives

To register your interest about becoming a platelet donor click [here](#) to access our dedicated website, or call us 0300 123 23 23. One of our staff can then check your eligibility and answer any questions you may have. For your convenience they can book you an appointment to give a sample alongside your next blood donation.

A/B negative group platelet donors are particularly in demand as their donations can be given to patients with blood groups other than their own. This can be vital in an emergency when there is not time to test for a blood group.

What are platelets?

Platelets are disc-shaped cell fragments in the blood which help it to clot. Under the microscope they look like small plates - hence the name. If you cut yourself, platelets immediately move to the cut area and stick together to form a plug to stop the bleeding.

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DIGITAL UPDATE

Online service is on target



We know time is precious for our donors so we are striving to make our online service as efficient and easy to use as possible.

Last November we relaunched the service and now almost half a million of you have registered for our on line service, with 80,000 of you making use of our mobile app version. The relaunch has meant donors can enjoy new and exciting features such as searching for and booking appointments in real time. Since the relaunch there have been over a million transactions by donors.

But we want to achieve more and we're starting phase two of the online service early next year. We've listened to your feedback and are preparing some enhanced features to the service including session search results ordered by date and time along with app messaging. Watch this space for more online updates.

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