

Celebrating Inspirational Clinical Leaders in Haemoglobinopathies

Let us introduce you to our first inspirational woman of haemoglobinopathies - Dr Clare Samuelson!

Consultant Haematologist and Training Programme Director based at Sheffield Teaching Hospitals, which is a Specialised Haemoglobinopathy Centre and Haemoglobinopathy Coordinating Centre for Yorkshire and the North East for sickle cell disease.

As part of my training, I spent 2 years working on genome editing treatments for haemoglobinopathies including thalassaemia and sickle cell disease, as research fellow at the Fred Hutchinson Cancer Research Centre, Seattle, US.

I chair the UK NEQAS Haemoglobinopathy diagnostics programme. UK NEQAS provides an assessment of quality and accuracy of laboratory tests, so in this role I help to ensure that laboratories conducting tests for haemoglobin disorders are delivering correct results.

My main professional interests are in the care of individuals with sickle cell disease, thalassaemia and rare inherited anaemias, and research to improve the treatments available. I also have an interest in Healthcare Ethics, and have taught on this subject at Leeds University after completing a Master's degree in this area.

What is the best part of your leadership role?

I am very fortunate to work with excellent and inspiring specialist teams, in both Sheffield and Bradford, who are very dedicated to making sure our patients receive the best care possible. Working together to look after our patients – and seeing the difference that makes to people's lives – is the most rewarding part of my work.

What is the most challenging part of your leadership role?

Trying to deliver a world-class service to patients with limited NHS resources is difficult and can be very frustrating. Haemoglobinopathy services are under-funded and there are not enough specialist doctors, nurses and allied healthcare professionals. This must improve longer-term if we are going to continue improving the care we offer.

What are you most proud of doing?

I am enormously proud of the Haemoglobinopathy team in Bradford who have worked very hard to build an excellent service for our local patients. I am proud to be part of such a dedicated and caring team.

What does the idea of leadership mean to you?

I think that leading by example is key to being a good leader and supporting and encouraging the teams we work with. Having high expectations for the future direction of our services, and clear plans for how to accomplish these aims, is also vital.

Have you ever been in a situation that made you think that ‘women’ and ‘leadership’ are considered as two incompatible concepts?

Yes, and this was mainly due to a lack of role models I could relate to as I was coming up through training. This is improving, but we still have a long way to go before women and people from ethnic minorities have equal representation at the top of large organisations.

Who are the top three women you admire the most and why?

This is difficult – there are so many... I would start with my grandmother, who worked as a hospital dietitian and later as a carer, raised six children of her own and looked after many more through the years in Barbados, and was still dancing at her 100th birthday party recently.

Secondly, and without wishing to embarrass her, Dr Nandini Sadasivam. Dr Sadasivam spent time training me in specialist thalassaemia management earlier in my career, and always inspires me with her commitment and enthusiasm to improve treatment and services. Thank you Nandini for all your hard work and dedication to our patients in the North of England.

Viola Desmond – Canadian civil rights activist, whose is now on the Canadian \$10 bill. Her advice to us all was: “Do your little bit of good where you are, it’s those little bits of good put together that overwhelm the world.” She reminds me that whoever we are and whatever we do, we can contribute to making things better and fairer. What is the most important piece of advice you have been given?

To be strategic and deliberate about achieving goals – and that things which are not possible now might become reality in the future.

What did you dream of doing when you were a little girl?

I wanted to be a farmer at one point (I’m not quite sure why!), but I knew from an early age that I wanted to be a doctor and to help people.

What are your dreams for the future?

That people living with inherited red cell disorders will have access to better treatments and options for a cure in the future. I also want to see these conditions better recognised and services properly resourced in all areas of the country.

What is the most important message you want to send out to young women thinking about pursuing a leadership role in healthcare?

We need you – we need your skills and your qualities in leadership roles. Many of us suffer from ‘imposter syndrome’ but don’t let that stop you. Find mentors and role models along your journey and keep going.



Celebrating Inspirational Clinical Leaders in Haemoglobinopathies

Let us introduce you to our second inspirational woman of haemoglobinopathies - Dr Nandini Sadasivam!

I have been a Consultant Haematologist for over 5 years now. My career path into haemoglobinopathy was shaped by the quality improvement and patient safety work I was involved in as a first-year consultant. I continue to do this work in haemoglobinopathy having had the support from Dr Farrukh Shah (who is currently the Medical Director of NHSBT) and Dr Josh Wright (who is currently the president of BSH) who believed in me in my early years as a consultant and supported me through challenging times to highlight health inequalities.

It is a privilege and honour to be the HCC Network Lead for North of England for Thalassemia and Rare Anaemia Network. I also am the adult thalassemia lead for the national haemoglobin panel, steering committee member on the NHR and organise monthly CPD as the education lead for the NW BAPIO.

What is the best part of your leadership role?

I am now in a position, as the HCC Lead, to be able to bring about a positive change to the haemoglobinopathy services for the North which is to improve patient experience and outcomes. This was not possible 5 years ago.

What is the most challenging part of your leadership role?

Breaking the barriers of stereotyping and discrimination a woman can sometimes face holding a leadership role. I have faced both sexism and racism. I have used this experience in a positive way to raise awareness and highlight these issues, so it is thought about earlier.

What are you most proud of doing?

Standing up for what is right and being a patient advocate.

What does the idea of leadership mean to you?

Leading by compassion and empathy. Having humility and leading by example are really important qualities I see in a leader.

Have you ever been in a situation that made you think that 'women' and 'leadership' are considered as two incompatible concepts?

For me personally, I have not however there are barriers to overcome and raising awareness of these barriers are important. It is not always visible to others.

Who are the top three women you admire the most and why?

- ◇ Dr Lisa Newton
- ◇ Dr Farrukh Shah
- ◇ Dr Shivan Pancham

They all have qualities that I see in a great leader: humility, compassion, empathy, and assertiveness and I really look up to them.

What is the most important piece of advice you have been given?

Always believe in yourself and your ability.

What did you dream of doing when you were a little girl?

I always wanted to become a doctor as a child. It is a noble profession where you are able to make others feel better by the treatment given. It is powerful to be able to have that impact. My dad is still very much my role model - being a medical Doctor and a leader himself he reinforced my dream.

What are your dreams for the future?

I would really like to see my patient group in the north have equal access to good quality treatment as any other chronic disorder does in the UK. I would hope to take on a senior leadership role in the future if opportunities arise and promote equality, diversity and inclusivity.

What is the most important message you want to send out to young women thinking about pursuing a leadership role in healthcare?

You may face some barriers as you take on a leadership role. You will need to recognise and overcome them with the right support network behind you. It is important to have good allies who you can turn to for advice and guidance.





Celebrating Inspirational Clinical Leaders in Haemoglobinopathies

Introduction: (Who you are, professional journey, achievements to date)

I am Noémi Roy, I am a consultant haematologist in Oxford. I look after people with inherited anaemias- this includes sickle cell, thalassaemia and rare inherited anaemias. I do clinics in Oxford and all around the Thames Valley region. However, I also work nationally and internationally on trying to improve care for people with inherited anaemias. This work basically boils down to lots of meetings, and lots of paperwork, but it is important because together we're able to write better guidelines, make sure that people are getting access to state-of-the-art diagnostic tests and treatment plans.

What is the best part of your leadership role?

The best part is working with colleagues from all over the country and sometimes in other countries who are all passionate about improving care for inherited anaemia patients. I learn so much from them, and we work in a very synergistic way, meaning that I feel that as a whole we achieve more than just the sum of our parts.

What is the most challenging part of your leadership role?

I think the hardest part is that often there are obstacles we are facing that really shouldn't be there. I hate having to fight bureaucracy, poor IT systems, and horrible things like systematic racism. And in this day and age, we do struggle with failings in the NHS that again could have been avoided.

What are you most proud of doing?

Me personally, I am most proud of the patient involvement and patient advocacy work I do. I have learned so much from patients, their strength and resilience are so humbling. And I never stop marvelling that no matter how much I think I know, I have yet more to be taught by my patients. Seeing people living with sickle cell presenting their work at the ASCAT conference made me so proud. That they should share the platform of great doctors and scientists is only right.

What does the idea of leadership mean to you?

Practicing what you preach. For me a leader is someone who behaves in a way that embodies what the whole system is trying to do.

Have you ever been in a situation that made you think that 'women' and 'leadership' are considered as two incompatible concepts?

I think that unfortunately we still do bump into this attitude too often. Women are often made to feel that motherhood will prevent them from being 'successful'. Of course, it depends how you measure success, but motherhood is by far the most wonderful and rewarding aspect of my life.

Who are the top three women you admire the most and why?

Ooh that's a difficult one! I'll steer clear of my haematology heroes and go for: Firstly, I would say Harriet Tubman- I grew up in the US and learned about this woman who helped several hundred slaves escape by leading them along the "Underground Railroad." She didn't just do the trip once, she put her life at risk repeatedly for the benefit of others. I admire her selflessness and her courage.

Secondly, I would choose Frida Kahlo- Not only do I love her paintings, but what I admire is that she did what she loved irrespective of what life threw at her or what others thought. She suffered from chronic pain and at times could not even get out of bed, but this did not keep her from expressing herself.

Finally, I choose my mother! She raised 4 girls into 4 strong independent women. She always made us feel that we could do what we wanted in life and that we would always find our way. I very much have found mine, and I am very grateful to her.

What is the most important piece of advice you have been given?

I would say that it is the fact that it's possible to change your 'head tapes'. This is something I learned as part of a course called Springboard, which was started by two women who designed it for women working in the BBC many years ago. 'Head tapes' are the things you tell yourself over and over again in your head like "I'm so useless" or "I'll never manage to do this" which unfortunately many women have going round and round their mind all the time. It's not easy to change these because they are so engrained in us, but I was so grateful to the Springboard programme for teaching me how to change them into positive empowering ones.

What did you dream of doing when you were a little girl?

I just wanted to be a doctor; I don't think I dreamt anything specific beyond that. I also wanted to have a family, and I could not be happier than I am with my amazing family, and on International Women's Day I celebrate the opportunities my daughters have to be who they want to be. I am filled with awe and wonder as I watch them grow each and every day.

What are your dreams for the future?

For positivity. For people to see that what makes them alike is more important than what makes them different. For rifts to be healed- between individuals, and between nations. Between our species and the planet which hosts us.

What is the most important message you want to send out to young women thinking about pursuing a leadership role in healthcare?

I would say surround yourself with people who believe in you and support you. Don't be scared to ask for help. Approach the people you admire and ask them explicitly if they will mentor you. Different mentors will teach you different things- have several mentors at once. Make detailed 5-year plans for yourself and review them once a year. And don't forget to look back every once in a while, to see the progress you've made. It's too easy to always be focusing on what hasn't been done yet and how much more there is left to do. But you need to also take a look at how far you've come.

Celebrating Inspirational Clinical Leaders in Haemoglobinopathies

Let us introduce you to our third inspirational woman of haemoglobinopathies – Sandy Hayes, Lead Haemoglobinopathy Nurse!

Adult & paediatric registered, Sandy trained in New Zealand, working there, Melbourne, GOSH & Oxford (OUH). Specialist qualifications in paediatric oncology/haematology, cancer nursing, BMT nursing, Haemoglobinopathies.

My professional journey has been long and varied, I started my training in 1983... I have always been interested in improving the care of patients and a lot of the time that is about understanding what the patients want/need and improving how services are delivered, run and managed.

I have been a ward sister twice, quality manager, specialist nurse, clinical lead. When I look back, my achievements have been varied and numerous: implementations of novel initiatives such as the Nursing Process, creating nursing care plans, developing chemotherapy training and competence in New Zealand/Australia/OUH, first ward to combine medical notes so nurses wrote in the same place as doctors (this was then rolled out when I moved to adults, then across the whole trust (1990's!)), developing the first competency assessments at OUH for central line care, chemotherapy and acute care; developing the acute skills of the ward nurse to ensure high level of acute deterioration recognition and patient management, undertaking the first physical assessment and history taking module at Oxford Brooks University in '96. Leading on the development of the cancer and haematology centre for the department and being heavily involved in ward design. Advocacy for patients, getting patients involved in design of ward and new ways of working.

I have been lucky enough to receive and be exposed to excellent leadership and management training and great role models. As the quality manager for BMT I was able to support the establishment of quality frameworks across the whole haematology department, so each sub speciality has its quality meetings with a focus on service development and quality improvement... I also brought this to Red cell when I started.

I have always been able to get people to listen to me and trust me to do what I said I would do. I have been the first woman and first nurse as the Clinical lead in the OUH Dept of Clinical Haematology. I am currently leading on CAR-T implementation.

As the first haemoglobinopathy nurse in Oxford I had the joy (and freedom) of setting up the nursing service, the wider service, collaborating with patients and regional colleagues to establish the regional clinics and MDTs, sorting out protocols, patient information, learning and sharing my passion for this part of my career. Governance and patient pathways are also another of my passions, so being involved in peer review has been a real joy and privilege. I just enjoy bringing new things and ideas to the table to see where they may go, I am not afraid to try and not succeed.

What is the best part of your leadership role?

Improving things...doesn't matter what! Watching people grow and develop, facilitating, enabling, encouraging others, sharing my learning and supporting people to develop their knowledge and skills. Putting the patients at the heart of what we do. I also like to be able to influence the local and national agenda.

What is the most challenging part of your leadership role?

The lack of time, not being able to sort everything out! I am due to retire soon.

What are you most proud of doing?

Always putting patients 1st, challenging the status quo & asking the question 'but why?'

What does the idea of leadership mean to you?

Leadership is about knowing who you are as a person and leader, knowing your style and being prepared to learn new skills and ways of doing things. It's about:

Being clear on your role and role of others, leading from the front or from behind ensuring everyone is clear about the goal. Open communication and the whole team being aware of what is going on. Sharing your skills and knowledge. Challenging and being challenged. Growth, both personal and professional and creating an environment where both are possible and realised/offered for everyone. Managing change and taking others with you. Being bold enough to try new things.

Have you ever been in a situation that made you think that 'women' and 'leadership' are considered as two incompatible concepts?

Never, I don't believe it, I've always proved people who maybe think this, very wrong, we can do anything.

Who are the top three women you admire the most and why?

I don't do idols or 'admire the most', I never have. I can generally find something to admire and learn from in most people.

What is the most important piece of advice you have been given?

Be true to yourself and find a way of saying things so people hear you.

What did you dream of doing when you were a little girl?

Accountant or architect.

What are your dreams for the future?

To retire in 2023 and to be able to travel at leisure not tied to work or school holidays!

What is the most important message you want to send out to young women thinking about pursuing a leadership role in healthcare?

Be educated, learn about leadership and management, understand your own strengths and weaknesses, set out to develop new skills, use someone you hold in esteem as a coach, look around you for examples of what has gone well and what went badly and constantly learn and reflect. Don't be put off and don't be scared to move around and move sideways to get a varied experience. And lastly, always ask why.