

QVH NEWS

Autumn/Winter 2024



Janie Hochkins with Mike

"I want to live through these hands and give them the life they now have given me."

Mike, Bilateral Hand Transplant Patient

Healing hands

As a specialist surgical hospital, our teams are always collaborating and sharing best practice with other organisations to benefit our patients. So it is not uncommon for our expertise to be sought out to enable patients to be treated closer to home, as was the case with Mike who came to QVH after an incredibly unique operation.

Mike is one of only ten people in the country to have had a double hand transplant after undergoing a pioneering operation under the team at the UK Hand Transplant Centre, in Leeds, led by Professor Simon Kay OBE. Mike had fallen ill on Christmas Day 2017 after contracting meningitis, which led to the devastation of losing both his hands and feet.

Now, many years later, he received a bilateral hand transplant at Leeds General Infirmary, before coming to QVH for his aftercare.

Janie Hochkins, Lead Nurse for Hands, was one of the first people to meet Mike when he came to us. And Mike is the first double hand transplant patient we have cared for.

She said: "I felt honoured and privileged to meet Mike on his maiden visit to QVH.

"When I saw Mike for the first time in the Hand Clinic, at that point, he had only seen his fingers. This meant that removing the dressings and fully revealing his new hands was quite an emotional time, not only for Mike and his wife Julie, but also for myself.

"Once finished, we then spent almost two hours with the hand therapy team where Mike met Katherine, Kirsty and Fiona, all of whom would be looking after him over the coming months.

"Mike is an inspiration and has a very positive outlook on life, despite the traumas he has been through over the last six years. He still has a long journey ahead of him but his resilience and determination, along with the support of his wife, will see him through."

Mike said: "What a tremendous gift to give. I want to live through these hands and give them the life they now have given me.

"I am overwhelmed by the potential in this gift of hands and the superb care given to me. Everyone is at the top of their game - thank you all."

Mike now campaigns to raise awareness of the risks of disease and recently addressed a meeting in Paris of the World Health Organisation, which has drawn up a global road map to defeat meningitis by 2030.



▶ Thanking 'magic'



▶ Mus win



▶ Star legacy

Could you become a QVH member or a governor



From our CEO

Bob Marchant, President of the League of Friends, who funded the previous scanner, with James, cutting the ribbon on our new CT Scanner.

Welcome!



This edition of QVH News coincides with me completing my first year as Chief Executive Officer here at Queen Victoria Hospital (QVH). When I first came I was impressed by the warmth and enthusiasm everyone has for their work and the organisation and that has not changed. The compassionate care given to the patients and desire to always strive to do better is one of the things that makes QVH such a special place and one that I am proud to be part of.

We have achieved a lot in the last 12 months, some of which you will read in this newsletter. Like the arrival of our new £750,000 CT Scanner, pictured above. This will increase our CT capacity by around 20%, and is an important part of our Community Diagnostic Centre service, providing greater access for patients who need a scan. And there is more for us to do in the coming months, including launching our new organisational strategy as we take our hospital forward into the next chapter of its unique story.

If you would like to become involved in our hospital why not consider becoming a governor? You can find out more about what it is like from Janet, one of our current governors, on [page 8](#). Or why not support our QVH Charity which allows us to go above and beyond for our patients? Find out more on [page 7](#).

Happy reading,



James Lowell
Chief Executive Officer



P.S. if you use social media please follow us! We regularly share updates and news so you can always find out what QVH is working on there.



Jeanette is better than ever thanks to "magic" Andy

'Don't worry, I'll look after you.' Nothing out of the ordinary in that short sentence is there? But to Jeanette, having just learned she needed a second breast Cancer operation 20 years after her first, they were words of magic.

Jeanette, 73, from Brighton, had been referred to QVH, and it's here, on her first consultation, that she met **Andy Mellington**, Consultant Plastic Surgeon, who provided those words of comfort.

She said: "It was a huge shock, Cancer again 20 years after the first time. This time the only option was a full mastectomy and there was not enough skin on my left breast for an implant. When I went and met Andy straight away any fear about my body just disappeared.

"I was more than happy to put my body in Andy's hands knowing all would be fine. It was when Andy left the room and was passing me, when he gently put his hand on my right shoulder and said, 'Don't worry Jeanette, I'll look after you'.

"It was a fleeting moment but it meant the world to me. Those words were like magic to me. From then on I didn't worry about anything."

Jeanette was so moved by the care she received she nominated him for our Outstanding Patient Experience Award in the Star Awards – which he won.



She said: "I honestly believe you can teach anyone, with the right aptitude, the ability to be a surgeon, but what you can't teach is the ability to put a patient's mind at rest. That has to be the most important thing, surely. Andy was superb, and that's why I nominated him. He fully deserved to win."

Nearly 18 months on from the operation and those 'magic' words, how is Jeanette feeling now?

"I feel he has restored my body better than it was before. How marvellous is that?"

The Outstanding Patient Experience Award was just one of ten handed out at our Star Awards on 12 July, that were kindly supported by our QVH Charity.

It was an amazing opportunity for us to celebrate the hard work, dedication and commitment of colleagues from right across our organisation. It was a great evening. Here's a selection of the winners.



Staff Awards 2024



QVH changed Carol's life around >



> with care and understanding

For Carol, her first visit to QVH literally changed her life. It was, she says, "like a light had come on in my life again."

Back in April 2014, Carol, from Bexhill, woke up one morning and saw in the mirror that the right side of her face had dropped.

She immediately knew it was Bell's Palsy.

Carol went to her GP and was given steroid medication. A week later, and still in pain, she saw another GP and was told the pain she was feeling was Shingles in the ear. Another eight weeks of pain passed, and then a hospital stay and a week of tests, before she was finally told she had Ramsey Hunt Syndrome – which is when Shingles affects the facial nerve near the ear. She later learnt that had she been given anti-viral medication as well as the steroids within the first 72 hours of her initial symptoms, it could have made a difference to her long term condition.

In summer 2015, over a year since she first went to her GP she was referred to QVH's Facial Palsy therapy team. And her life changed. The light came back on.

Carol said: "It was the first time I really spoke to someone who knew what Facial Palsy was and what had happened to me. Sympathy is one thing but knowing that someone fully understands the condition was a true blessing. My visits to QVH literally changed my life. They went out of their way to help me. They gave me time.

"It was like a light had come on in my life again. I get quite emotional when I think about it because it was just that. They gave me the confidence to feel that I could help myself improve. I am eternally grateful to all of them.

"It was here that I was told my condition was called synkinesis, (when the face makes unwanted movements, usually brought on by Bell's Palsy)."

Carol says the treatment she receives is more than just muscle therapy. The sessions have given her the strength to deal with a condition that makes it difficult to face the outside world.

Catriona Neville, Extended Scope Practitioner in Facial Palsy, says their work is important in helping people with the condition to see a positive future.

She says: "I've had patients who have lost their jobs, left jobs and left relationships because they haven't been able to kiss their partner and their whole relationship has broken down.

"I've worked with patients who have said to me that their face might not look severely affected by their Facial Palsy but actually internally, the feel of it is incredibly painful and distracting and intrusive to their thoughts."

QVH experts have joined Carol in calling for more awareness about Facial Palsy, which affects around 100,000 people a year in the UK. It is often misdiagnosed and those with the condition can struggle to be referred to specialist services like ours. Meanwhile our team are supporting clinical colleagues both nationally and internationally to understand more about the condition and to train them to support their own patients.

Around
100,000
people are affected by Facial Palsy in UK.



- > QVH has the UK's **first and largest** expert Facial Palsy service, opened in 2007.
- > QVH gets **200 new referrals a year** to its Facial Palsy service.
- > The youngest QVH patient is **under 2** and the oldest in their **90s**.
- > Patients come from **all over UK** – from Jersey to Tyneside.
- > The **multi-disciplinary team** treat most difficult and complex Bell's Palsy patients.
- > They educate colleagues from the UK and internationally, helping more people get **the specialist help they need**.



Stacey's smile journey puts QVH cleft patients in the picture



Stacey's son, Dylan

Stacey Hussell is one of our medical photographers who, inspired by her own journey, has created a project called Smile Journey, to support some of our youngest cleft patients. Through it, she and our medical photography team are offering to take a keepsake picture of the baby or child for the parents to take home, separate from their clinical photos. Here's Stacey's story.

It started with a smile, the one she lost as a child. And it's carried on with the one she re-discovered on her wedding day, and the one she saw on her baby son's face that inspired her to share the smiles of babies and child cleft patients through her job here at QVH.

Stacey was born with a cleft and had her first surgery at four months old, on her lip, followed by her palate at 15 months. When she was young having a cleft didn't affect her. She was confident, loved dancing, she was happy, smiley. But then when she went to secondary school things changed. The staring. The name calling. The bullying. No more dancing, no more smiling.

University was easier, confidence returned slowly. Then after graduation Stacey became a photographer, and worked in a medical photography team at a hospital. She knew she wanted to use her skills and her life experience to help other people with clefts. She just didn't know how.

Her personal life was going well. She met Dave in 2014 and two years later they married. She was smiling again. In 2018 she had a daughter, Niamh, who was not cleft affected. Then during her second pregnancy, a 20 week scan detected a cleft lip. Further scans confirmed it. Dylan would be born with a bilateral cleft lip, probably palate as well. Through this difficult and worrying time, something shifted in Stacey: she now knew how to use her photography to help others with clefts.

Here at QVH she set up a project called Smile Journey, where she and the team take lovely images of baby and child cleft patients for their parents to take home.

"When I returned to work after my maternity leave with Dylan, I was asked if there was anything I wanted to do and I said something with my photography to help parents with babies with cleft," said Stacey.

"I was given the go-ahead and that really inspired me to get a plan together. We have a cleft clinic here at QVH, where patients come for treatment following surgery at Guys and St Thomas' in London. Throughout their time with us we take a number of photographs that mark their clinical journey, kind of before and after surgery. I thought, why don't we give them a photograph that shows the child, a portrait, one that shows a smile."

Stacey said: "Now the parents come in with their child and myself or the team ask if they want a professional portrait taken of their child, a keepsake for them, something that shows the child smiling, natural. Parents really like it."

She added: "Today there is general acceptance around almost every kind of difference, which is how it should be. But I still feel that anyone with a facial difference – Facial Palsy, burns, cleft – sometimes still feel stigmatised.

"I hope my work here can help educate people and make people aware what the cleft journey can be like, and maybe the stigma will be lifted and my boy won't get bullied at school like I was."

Dylan's birth inspired another big change: for the first time, Stacey started talking about her own cleft experience.

Stacey recalls: "I remember chatting with one teenage girl; she was considering jaw surgery, which I had myself - I've had 13 cleft-related surgeries in total, including seven here at QVH - so I took the time to listen to her and share my own treatment journey. I know she was grateful for that conversation, and so was I."

So what would Stacey say to someone going through their own cleft journey?

"If I could offer advice to someone who is navigating their own cleft journey, I'd tell them to reach out to others, whether that be family, friends, or community groups for cleft-affected individuals. It's all about connection. Share your story and talk to others about your experience. If you can find your people, you take a big step toward finding acceptance of yourself and discovering your own confidence.

"I'd also remind them that they are beautiful!"

And to smile.

Mus back to his best after Cancer thanks to QVH team



In early spring 2023 Mus was juggling his busy life as an account manager for a consultancy and his role as a local councillor, while spending his spare time trying to break his personal best in 5 and 10k runs. All that changed in March last year when his doctor referred him to us after treatment for painful ulcers on his tongue failed to work.

Mus went to the maxillofacial department where he had a biopsy taken. Two weeks later he got the results and the answer he was dreading. It was tongue Cancer. He was just 38 years old.

Mus takes up the story.

"It was all systems go. I had scans and then the operation. It went well but then I picked up an infection. This meant I spent another five and a half weeks in hospital and had to have four more operations.

"I was looked after by the Maxillofacial Dressings Clinic as well as the speech therapy department with Samantha Briggs, Principal Speech and Language Therapist, who was involved in my care and treatment, which has been positive. The QVH Macmillan nurses were so helpful in responding to me, gave me any information I needed and were on hand with anything. Everyone has been amazing - professional and lovely."

After nearly six weeks, Mus was able to go home. And that's when his battle to get well began in earnest.

"I was really happy to go home – though my care was so good. Going home was the only 'up' moment I had for a while," Mus recalls. "The side effects from the radiotherapy I had at Royal Surrey were brutal: constant sore throat, ulcers, constant coughing, dry mouth but at the same time having to combat thick and sticky mucus and not being able to speak. I had a "peg" feeding tube into my stomach for six months to keep me fed."

Over a year later Mus is back in good health and can reflect on the care he received at QVH.

"My overall medical journey experience hasn't been nice but the care I've had from the hospital can't be faulted.

"To anyone else coming here as a patient I would say stay positive and listen to the professionals, speak to people if you need to as they have the information that can help.

"Don't be afraid to ask, no question is too stupid to ask! So don't be afraid to say what you want to say.

"Now I see Mr Prakash Patel, the QVH surgeon who performed my surgery every two months"

The message from Mus to people recovering from treatment is to 'count up all the little wins, they amount to the big wins. Stay strong and keep moving forward as best you can!'

Mus is certainly doing that, back to work, back to his seat on the council, and those personal bests he'd been chasing?

I'm back to exercising and running and just completed PB's in both 5 and 10k – I have my old life back!





Ava, centre, with Archie and his wife Constance.

When Ava met Archie: A star legacy helping change lives to this day

Ava Gardner is a legend of the silver screen and a bona-fide Hollywood superstar, famous for films such as 'The Killers' and 'Show Boat,' during a 50-year career.

What is less known, is her connection with QVH which began in the 1950's, and is still going strong to this day.

It started on a ranch in 1957 in Peralta, Spain. One October day Ava suffered a fall from a horse which resulted in a haematoma on her right cheek. More serious than the injury itself, was the hit Ava's confidence took from the bruising on her face. She didn't work for two years.

It was during this time Ava sought the advice of one of the world's leading plastic surgeons, Sir Archibald McIndoe here at QVH.

Archie, as Ava came to call him. He treated her, continued to follow her progress, and assured her that the haematoma would go away in time.

In recovering from the fall, Ava became more and more involved with the airmen who were being treated for burns at the hospital, many of whom formed The Guinea Pig Club.

Ava said her involvement with these brave men helped her. "It was the best possible therapy for me."

In her autobiography, Ava: My Story, she said: "I met a lot of them and we danced and laughed together. They were so brave I could have wept.

"Archie told me my visits did them a lot of good, but I'm sure they helped me more than I ever helped them."

Ava passed away in London in 1990, and Queen Victoria Hospital was named as a beneficiary in her estate. Ava's legacy of giving continues to support our patients as well as staff, and we are proud and so grateful to be supported by The Ava Gardner Trust to this day. **Over the years this has amounted to £650,000.**

Our QVH Charity has been fortunate to receive some generous donations from supporters after they have passed away. These legacies have helped transform the way we look after patients and staff. Every single donation and gift we receive is incredibly precious. A gift in your will is just one of many ways that you can choose to support our work and make a real difference to people.

People like Ray, who came to us following an operation to remove Cancer in his mouth. He was finding it difficult to sleep in our Critical Care Unit. That's where QVH Charity was able to help by funding a trauma chair to sleep on. This helped him become much more comfortable and allowed him to gain much needed rest.



Will you help Queen Victoria Hospital stay at the forefront of innovative care?



Please contact Camilla Lane on **01342 414 392** or visit our website **www.supportqvh.org** to find out how your support can help rebuild lives.

Find out more: email **qvh.supportqvh@nhs.net**

Janet, what's it like to be...

a governor

Janet Hall has been a governor at QVH since 2023.

Here she explains more about the role and why you should think about becoming a governor too.



Tell us a bit about your background?

I live locally and worked for the local NHS for 20 years before retiring in 2012. During the last ten years of my employment I set up and managed the Patient Advice and Liaison Service (PALS) and Public Engagement Service at Surrey and Sussex Healthcare Trust (SASH). In June 2023, I was elected as a Public Governor at QVH and became Deputy Lead Governor in November 2023.

What inspired you to become a governor?

After retiring I wanted to continue to contribute in some way to the NHS as I am passionate about making things better for patients and their communities. In my role as governor, I felt I could use my previous experience and skills to do this.

What have you enjoyed most or found rewarding in the role?

I like that QVH is a small specialist hospital with worldwide acclaim and lots of interesting history, whilst still being firmly embedded in its supportive local community.

I enjoy working with my fellow governors and working with the QVH management team. I am also looking forward to having more opportunities to work with members of local communities to get their feedback and represent their views.

What do you see as your greatest successes?

I have taken on the role of Deputy Lead Governor, which has been extremely interesting and made me realise there is a lot to learn! The role has involved regular meetings with my Lead Governor and the Chair of the QVH Board. They provide an update on what is happening in the hospital and allow us to raise questions and concerns from governors.

Would you recommend becoming an NHS governor?

If you have some time to give, an interest in supporting your local hospital and are keen to get involved in your community then you should consider becoming a governor.

What do you want to tell members about QVH?

I have found the hospital to be a small, welcoming Trust providing specialist care from dedicated, caring and friendly staff. It provides an essential local, regional and national service for reconstructive surgery, burns care and rehabilitation services.

How do you describe being a governor in three words?

Worthwhile, rewarding, interesting!

Could you become a QVH member or a governor?

Did you know you can be an important part of QVH by signing up to become a member? It is free and easy to join and it gives you the chance to show your support, help to shape our future and hear our news.

Interested?

You must be aged 18 or over and live in Kent, Surrey, East and West Sussex or South London. If you want to stay in touch with us but are under 18, or live outside these areas, you can become an affiliate member but will not be able to vote in elections.

To join please complete the form you can find on our website at www.qvh.nhs.uk in the members section. By giving us your email address we can keep in touch with you.

During September we will be writing to our members asking if they would like to stand as part of our upcoming governor election. We are looking for members of all backgrounds and experiences who are aged 18+ to put themselves forward.

People can also attend the Council of Governors meetings that take place. To see when the next ones are happening have a look here:

www.qvh.nhs.uk/for-members/public-meetings/

If you have any queries, want more information about becoming a member or a governor, or are already a member but want to update your details, please email Leonora May, Company Secretary, at qvh.corporategovernance@nhs.net