# RHNSupporter

Royal Hospital for Neuro-disability

Registered Charity No. 205907

NEWS FOR SUPPORTERS OF THE ROYAL HOSPITAL FOR NEURO-DISABILITY

SUMMER 2020

### RHN Supporters Walking For Charity

On Saturday 8th February, 50 people and one excitable dog turned out to defy the cold and walk 5 miles through the beautiful Wimbledon Common in support of the Royal Hospital for Neuro-disability (RHN).

The weather was kind and the walkers saw the final dry day before storm Ciara hit the country. The route followed footpaths through the leafy woodlands and past the common's famous windmill with a few puddles, horse riders and happy walkers along the way.

Our youngest walker Michael (pictured) aged 4, took on the route on his bicycle and did not stop the whole way. Along with his parents, Mariya and Sherif, Michael managed to raise £476! Another young supporter of the RHN, Luke Williams, was our first ever supporter to not walk, but run the entire route. Luke exceeded his fundraising target and collected a total of £655 in support of the RHN caring for patients with severe brain injuries.



After successfully walking 5 miles, the group returned to the RHN where they were treated to a hot lunch and awarded their certificates and gold badge for completing the walk.



Collectively, the Winter Walkers' raised an incredible £4,103. Each donation will, without a doubt, contribute immensely to the treatment, care, rehabilitation and assessment services the RHN provides for some of the most disabled adults in the UK.

The RHN would like to thank you all of the participants for taking part and supporting the vital work of the medical charity. It is down to them which makes the hospital's work possible giving people with serious brain injuries, a better quality of life.

The sequel of the walk, the RHN Summer Stroll, will take place on Saturday 12th September 2020, 10am.

You can take part in any walk, run, cycle or skydive in England, the UK or worldwide to raise money for the RHN. Take a look at our website for some examples of inspiration at www.rhn.org.uk/events or contact events@rhn.org.uk and 020 8780 4560 for more information.

We are currently offering half price registration for the famous cycling challenge, the Prudential RideLondon-Surrey 100, at just £7.50. With a fundraising target of just £400, you will receive a free RHN cycling jersey to wear on the 16th August, expert fundraising tips and an invitation to our 'Thank You' drinks reception in October. The registration deadline is Friday 29th May so be quick to secure your slot!



Every November the RHN celebrates the care and dedication of its staff with an annual awards ceremony. In 2019 the Excellence In Care Award winner was Health Care Assistant, Adama Bathily. Adama was nominated for his dedication and compassion, after he accompanied one of our patients on an overnight stay at St George's Hospital in Tooting.

As part of his nomination the team at St George's wrote,

"The care Adama gave was absolutely outstanding and the nursing team were blown aware by the kindness that he showed. It was a difficult night shift, as the patient was requiring intensive nursing and physiotherapy throughout, and he did not sit down for one moment. He held the patient's hand and talked to her continuously. They clearly had a wonderful relationship, and importantly he played a critical part is us being able to care for her."

### **Award Winning Care**

An interview with Health Care Assistant Adama Bathily

We caught up with Adama to find out more about his role as a Health Care Assistant and why he's so passionate about it.

### How long have you worked at the Royal Hospital for Neuro-disability?

I have been at the RHN for eight months. Before that I worked in a nursing home for nine years as a Health Care Assistant, and then briefly for the NHS. My role in the NHS was more office based though and working at a desk all day didn't suit me. I wanted to return to front line health care. My wife is a nurse at the RHN and she encouraged me to apply for a job here. She told me it was an excellent place to work and that the role was just what I was looking for. She was right.

### What attracted you to a job in healthcare?

I believe that you should follow your instincts and pursue the job you are best suited for. If you do that you will rarely go wrong. I enjoy caring for people. We need to look after each other and the RHN has many people in need of our help. I want to make a contribution to the world we live in, and achieving that by doing something I love makes me feel good.

### What's the most rewarding aspect of your role as a Health Care Assistant?

My job makes me feel valuable. We have many patients who have suffered physical and emotional trauma, who were fit and healthy, but who are now helpless. You can't turn your back on someone when they need help, and I consider myself very fortunate to be in a position where I can offer that help. The relief you see in patients when you're there to help them wash, dress, eat or just to be with them is enormous, and I get a great sense of achievement from that.

#### Caring for a person with a severe disability can be physically and emotionally draining. What do you do to cope with the challenges of your job?

The healthcare needs of a patient can change very rapidly, and as a Health Care Assistant you are with that patient for many hours in the day. You don't know when a change might occur so you have to be ready for it, physically, emotionally and mentally all the time. We have a great team in Haberdasher's House. The staff are dedicated and very supportive, especially our Ward Manager. It doesn't feel like being at work. It is our home, and I am never alone. I know that my colleagues will always be there to support me, and I am there to support them too. The hospital Chaplain, Geoff has also been a great support for us when we have faced the emotional challenges of our job, and I would like to say a big thank you to him.

### What do you imagine your future will be in health care?

The values of the RHN, of seeing the whole patient, of having integrity, honesty and a willingness to learn, are values that I share and I am very lucky to be working for a charity where everyone is immersed in those same values. I feel proud to work here. I hope to continue training and become a nursing assistant, and eventually a nurse. I will definitely remain in front line health care.

### Support the RHN with Amazon Smile

If you like to shop on Amazon, you can now support the RHN by signing up to Amazon Smile. Just go to <u>http://smile.amazon.co.uk</u> and search for the Royal Hospital for Neuro-disability in their list of supported charities. Once you've signed up, remember to access Amazon via the Smile page, and for every purchase you make a small donation will wing its way to the hospital. amazonsmile

Already love Amazon? How about using AmazonSmile! The same great Amazon you love but with .05% of the profits being automatically donated to us!

### **Communicating is Amazing:** Meet RHN patient, Bernadette.

The RHN's Compass Service is a specialised service providing Assistive and Rehabilitation Technology solutions, including Augmentative and Alternative Communication (AAC) tools, to RHN patients.

AAC tools are methods of communicating that can be used alongside, or instead of, talking. They are designed for patients who, due to their brain injury, have difficulty communicating using speech and who may also have physical difficulties which impact further on their ability to communicate.

Our ability to communicate complex ideas and feelings is a vital part of being human, and losing that ability can have a profound psychological impact. For patients suffering a serious illness or disability it can be doubly isolating, as they are unable to communicate effectively with their carers and doctors. We spoke to one RHN patient, Bernadette, who explained how access to a specially adapted nurse call switch made a huge impact to her recovery and wellbeing.

In February 2019, retired nurse Bernadette developed Guillain-Barré syndrome. Guillain-Barré syndrome is a rare, but serious, autoimmune disorder where the immune system attacks healthy nerve cells. This leads to weakness and numbness in the limbs, and can cause paralysis. The cause of Guillain-Barré syndrome is unknown, but it's typically triggered by an infectious illness, such as stomach flu, or a lung infection.

Bernadette's illness was severe, and she spent ten months in an acute hospital, unable to move or speak, and with a ventilator assisting her to breathe. In November 2019, she was transferred to the RHN to begin a programme of rehabilitation. Now able to speak she describes her time in intensive care as extremely isolating.

"Not being able to speak, or call for help makes you very anxious. All I could do to attract attention was stamp my foot, and often it was another patient on the ward who would notice I needed assistance, and call a nurse for me."

As well as the practical challenges caused by not being able to communicate, Bernadette found it emotionally distressing too.

"It's also a very lonely experience when you can't move or speak. I couldn't even turn the TV on to distract myself. I was trapped with my own thoughts, wondering if I would get better again, for a very long time."

Fortunately, once she was admitted to the RHN, our Compass Department were immediately able to assess Bernadette's communication needs and abilities, and provide a solution she

#### The RHN's Compass Team





could use. A simple switch, which she could operate with her head, allowed her to call for assistance even when she was alone in her bedroom.

### "It was a miracle when the team fixed me up with my device. It's amazing and I owe them a lot."

As her programme of Physiotherapy and Occupational Therapy continued, Bernadette's physical strength and co-ordination improved, and the Compass team were able to modify her device, first so that she could use it with her shoulder, and then eventually with her hand. Compass were also able to provide some sessions using a virtual reality programme in the Compass computer room to help build Bernadette's range of movement and arm strength.

#### "I can't emphasise how important it is to be able to communicate when you're as ill as I was, because you're reliant on your carers for everything."

Bernadette's switch is a relatively simple device, costing less than £100, but many of our patients require more complex systems to enable them to communicate and also maximise their independence. Now that she's regained some of her strength and co-ordination, Bernadette has access to an Environmental Control Unit in her room. This system allows her not just to call a nurse, but to turn her bedroom lights on and off and change the channel on her TV. To install one for a patient can cost over £1,500. For the most severely disabled patients, who may only be able to move their eyes, a wheelchair mounted communication system can cost over £5,000.

Not all of our patients will qualify for NHS funding for these devices and may not need them forever if their rehabilitation is successful but, as Bernadette's experience has shown, even a simple piece of equipment like a switch can have a profound effect on a patient's mental wellbeing, their health and their recovery. That's why we're asking for your help to raise £50,000 to make sure every patient can have access to assistive technology solutions which work for them and which aid in their rehabilitation. Bernadette described her switch as amazing. You could do something amazing today, and support our appeal for the Compass Team. Your donation could make all the difference to a patient living with brain injury.

### To find out how to donate to this appeal, please turn to the back page for more details.

### From the Archives: The RHN and the birth of the National Health Service

The National Health Service came into being in the United Kingdom on the 5 July 1948. The scheme brought about the nationalisation of voluntary hospitals and local government hospitals into one national service, which included RHN. The Hospital had spent the years since the National Health Service Act of 1946 in a great sense of uncertainty (which had a serious impact on hospital finances) as to whether it would be incorporated and indeed, whether it should challenge or accept the decision.

Soon after passing of the 1946 Act the Hospital Chairman, Sir Edward Maclagan decided to write to the Health Minister, Aneurin Bevan, to ask whether the Hospital could be exempted from the Bill. He stated in his letter:

> "...The term 'Hospital', as applied to this Institution, is in some ways a misnomer. No patient is admitted unless his or her

disease is certified to

be incurable, although all that is possible is done, under the supervision of a visiting

doctor, to alleviate

the ailments of the

patients. The institution

was started in 1854 as an 'Asylum' and it has

regularly been refused

pecuniary help from

bodies like the King



Aneurin Bevan, Labour MP and Minister for Health 1945 – 1951.

Edward Hospital Fund and the [Metropolitan] Hospital Sunday Fund, on the grounds that it is not in line with other hospitals. It is, in fact, a Home, and it has always aimed at providing greater amenities to its patients than would be provided in a hospital..."

The Minister did reply that the government would consider the exclusion of the Hospital but in 1947, the Hospital was informed that it would be taken over. The Board acted swiftly and immediately challenged the decision. They contacted similar institutions, such as the British Home and Hospital for Incurables, Streatham; Royal Midlands Counties Home for Incurables, Learnington and the Jewish Home for Incurables, to see whether it was possible to have concerted action to avert the take-over. Discussions took place but each Hospital decided it should undertake its own case.





The RHN has always strived to provide a wide range of patient activities, aimed at improving mobility and quality of life.

The Hospital took the best legal advice possible and hired Sir Valentine Holmes (1888-1956), KC, and Mr F E Francis to advise them. They advised them to take the case to arbitration.

By 1950, the Hospital was still contesting the decision to join the NHS and the Hospital's finances were in a perilous decision. Under the NHS Act, the government could take over the endowments of the Hospital which would have further damaged the hospital and make it impossible to continue operating. The Ministry of Health were asked to postpone taking any endowments until after the arbitration hearing and they confirmed that would be the case.

At this stage, it became known that the British Home and Jewish Home were also proceeding by means of arbitration, and the three Homes and their advisors were very closely in touch during these proceedings. The first arbitration proceedings were for the Jewish Home for Incurables on 27 February 1950, which they won and the Ministry of Health did not appeal against the decision. Then on the 17 May 1950, the Ministry of Health wrote to the Hospital's solicitors informing them that the Minister had withdrawn his claim. As a result, the Royal Hospital for Neuro-disability remains an independent charity hospital to this day.

### The History of Speech and Language Therapy at the RHN

2020 marks 75 years since the Royal College of Speech and Language Therapists was established. This is the professional body for Speech and Language Therapists (SLTs) working in the United Kingdom. SLTs are allied health professionals with specialist training in communication and swallowing.

This anniversary led the SLT team to consult the RHN archives and look back at how SLT has developed at the hospital, parallel to advancement in the profession more widely.

SLT at the RHN dates back to October 1956 when the Medical Committee approved the appointment of one SLT for half a day per week. The first SLT to work here was aptly named Miss Swallow! The caseload consisted of 17 patients, most of whom had multiple sclerosis or Parkinson's disease. The early SLTs worked on speech production, vocabulary, reading and writing. Over the following years the number of patients needing SLT gradually increased and the range of neurological conditions experienced by our patients broadened. The department was expanded significantly in 1989 when the new Brain Injury Service opened on Devonshire and Clifden wards, and again in the 1990's when new transitional rehabilitation and neuro-behavioural services began.

Nowadays there are 12 SLTs and two SLT assistants working across the rehabilitation wards, continuing care services and the Compass team. At any one time around 100 RHN patients and residents are receiving SLT input and we work on a wide range of goals around communication, swallowing difficulties and tracheostomy care.

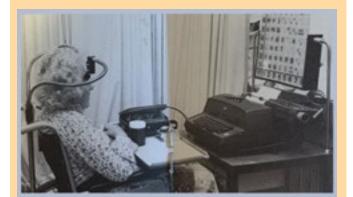
An area which has developed unrecognisably in the 64 years of SLT at the RHN is the use of communication aids. One of the earliest was the Possum: a typewriter which could be operated with light touch or by puffing or sucking air through a tube. This was introduced to the RHN in the 1960s and a photo of one in use by a patient was included in the hospital magazine. It opened up communication to a range of patients, but was far from portable!

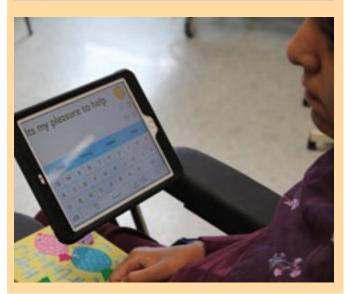
Communication aids later evolved as technology developed. By the 1980s many patients used digital devices and these could produce synthesised voices. Nowadays Compass provide us with the very best new technology to use with our patients including bespoke switches of all shapes and sizes, eye gaze technology and computer tablets.

Over time our work around swallowing disorders has grown. SLTs started treating patients with impaired swallowing in the 1980's as we were recognised as having specialist knowledge around the anatomy of the mouth and throat. In the early days treatment options were limited to non-specific exercises and altering food and drink textures. Now there is a wider range of evidence based therapy options including respiratory muscle strength training devices (which build the strength of the swallowing muscles) and surface electromyography (which traces the electrical activity of the swallowing muscles to assess function). The RHN SLT team is always looking to expand our therapy skills and adopt new technologies.

The FEES (fibre-optic endoscopic evaluation of swallowing) service started around 2005 and the SLTs started running it independently in 2007. FEES is an assessment where a small camera on a flexible endoscope tube is passed through a person's nose to look at how food and drink is swallowed and cleared through their throat. We now run a weekly clinic and it helps many patients and residents start to eat and drink, or work towards having their tracheostomy tube removed.

### The Possum typewriter and a more modern communication aid





The RHN SLT team are proud to advocate for patients with brain injury in the wider world. We train student SLTS and regularly run training courses attended by SLTs from all around the UK and abroad who learn about our work with neuro-disability. Our next course in November 2020 will look at cognitive-communication impairment; a condition experienced by large numbers of people with severe brain injury. We also contribute to research and policy development including recent guidelines for SLTs working with people in prolonged disorders of consciousness, and the current UK guidance for use of FEES.

Our aim as a department is to continuing growing and supporting patients with achieving their best possible outcomes in the future.

Alice Howard is an Advanced Specialist Speech and Language Therapist at the RHN. She graduated in 2010 from The University of Sheffield and has been a member of the RHN SLT team since 2012.

### Chaplain's Corner



RHN Chaplain, Geoff Coyne

As I write this I am looking out of my window and see the first signs of warmer weather and by the time you read this summer will be on the way. And having all have been through a very anxious and frenetic time because of coronavirus, summertime will be a good time to stop and reflect.

In the midst of all the busyness of life let's not miss the summertime moments – a beautiful sunrise, summer flowers, the warmth of the sun, the smell of a barbecue, a day at the seaside, the sight and sound of cricket and, of course, so many other things. Let's take the opportunity to slow down, take a deep breath of the summer scents and enjoy – even for a few moments.

But as well as enjoying let's make memories – spending time together with family, friends or special people in our lives and doing some of those summer activities whether it be the barbecue, the beach, the patio, the country walking or a holiday. Those memories will be rich with love, friendship, support and care and will give us strength for whatever we face in the future. And reflecting on them will also give us a deep gratitude for those who are in our lives.



### \_avender Remembrance Fund

Below are the names of past patients, volunteers and staff at the RHN, whose loved ones have chosen to set up a tribute fund and planet a lavender bush in their memory. The tribute lavender beds can be found in the RHN gardens. Please feel free to visit the hospital and take a look.

Adeh Murray Sellar Anne Prosser Antony Olley Avis June Smith Barbara Garnham Barbara Kelly Catherine Ann Fitzgerald Christopher Bedford David Driver David John Fincham David John Gillett Diana Merrick Eileen Dorothy Barrett Eileen McKay France-Raoul Chateau Graham Phillips

Graham Boiling Henry John Old Hugh Munro James Pirie Kamaljit Toor Lesley Jean Hyams Lucy Jane Denniston Margaret Deller Maud Riley Maureen Lesley O'Brien Megan Paton Megan Paton Megan Walters Michael Brocklehurst Michael Lindsay Neale Gordon-Wilson

Ghulam Sarwar

Patricia Burston Paul Loft Peggy Stannard Peter Gow Peter John Davies Peter John Davies Peter Newton Roger Smith Rosemary Ann Shurrock Sean Hamilton Shirley Gill Taranjit Kaur Chadha Ted & Gladys Black Trevor George Kingham Ved & Helena Aggarwal Winifred Warwick-Mayo

Lavender Funds are a way of celebrating the life of a loved one while helping others in need of our specialist care and support. After setting up a fund you will also have the opportunity to plant a special memorial lavender in our peaceful garden.

For more information please contact Isabel Barrett in Fundraising on 020 8780 4557 or at ibarrett@rhn.org.uk

### Dates for your diary

### **Superhero in the City**

#### Thursday 11 June

Looking for something fun? Whether you walk or run, become a superhero for the day whist supporting the RHN. Starting at Millennium Bridge at 6:45pm you'll pass iconic landmarks including the Tower Bridge, the Shard and the London Eye. You'll receive a free mask and cape of your choice. All we ask is for you to raise as much as you can. Entrance must be 8yrs+.

### **Prudential RideLondon Surrey 100**

### Sunday 16 August

Cycle 100miles in support of our patients and residents and take on the world famous Olympic route through London's closed roads.

There is a  $\pounds$ 7.50 registration fee which includes a charity cycling jersey and a fundraising target of  $\pounds$ 400.

### **Summer Stroll**

#### Saturday 12 September

Take a stroll with us this summer whilst raising vital funds for the RHN. This 5 mile walk starts at the hospital and heads through Wimbledon Common with a treasure hunt quiz (with the chance to win prizes!) and finishes back at the hospital for lunch. Registration is £10 per person, or £25 for a family with a fundraising target of £100 per person, and a family target of £300. This is set to be a fantastic day for all the family- dogs are welcome.

### **Thames Bridges Trek**

#### Saturday 12 September

Join over 2000 other trekkers and walk 25km over 16 of the Capital's historic bridges, with skyline views and a celebratory finish at Tower Bridge.

Join Team RHN for only £5 and pledge to raise £245. Contact the events team for other trekking events or visit our website.

### **Open House**

### Sunday 20 September only

Enjoy free entry for the Sunday only as we open our grounds and buildings to members of the public as part of the Open House London event.

There will be an archive display as well as guided tours. Please check our website for any updates.

If you would like further information on any of these events then please visit **www.rhn.org.uk** or contact the events team by email **events@rhn.org.uk** or call us on **020 8780 4560**.

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## Join The Royal Hospital for Neuro-disability for our 6<sup>th</sup> Annual Gala Dinner



The Royal Hospital for Neuro-disability (RHN) invites you to join their very special annual Gala Dinner on Tuesday 20 October 2020, taking place at the truly elegant Royal Automobile Club on Pall Mall, London.

With its classic architecture of marble fireplaces, chandeliers, mirrored panels and iconic car displays, the event is set to be as spectacular as ever. Guests will arrive from 6.30pm for a champagne reception followed by an indulgent three course meal with fine wine, entertainment and a live auction where guests have the chance to bid for a selection of exclusive prizes and experiences.

The Gala Dinner is a wonderful opportunity to host friends or clients in an impressive setting being one of the world's foremost private members' club! Tables seat 10 guests for £1,500, individual tickets are also available.

As the RHN is a medical charity separate from the NHS, all proceeds from the event will go towards funding specialist rehabilitation services and technologies suitable for the patients with profound disabilities arising from brain injury, which are not usually offered at traditional hospitals.





The event sold out last year welcoming over 200 guests. To secure your place and support a fantastic cause, get in touch with our events team. Call 020 8780 4565 or email events@rhn.org.uk

This event has been kindly supported by Healthcare Locum Recruitment Ltd.

### Please click <u>here</u> if you'd like to support The Royal Hospital for Neuro-disability's Compass appeal.

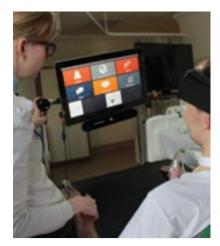
- **£30** will provide a simple switch, allowing a patient with communication difficulties to call for assistance.
- **£50** will allow a communication aid to be fitted to a patient's wheelchair.
- **£100** will provide a patient communicator with a range of pre-recorded messages.

Don't forget to let us know whether or not you're a UK tax payer. We can reclaim the tax on your donation and any future donations, to make your donation **25% more, at no cost to you!** 

#### Donate online: www.rhn.org.uk/online-donation / Or call: 020 8780 4568

You can also donate by post, sending your gift to: **Royal Hospital for Neuro-disability**, **FREEPOST**, **London SW15 3SW**. Using a stamp will save RHN money. When sending a donation by post, we would appreciate it if you could include your address and email details so that we can continue to keep you updated on our work.

If this project is fully funded by the time we receive your donation, your gift will be used for the general benefit of patients at the RHN.



Thank you for your support!