



## Welcome to the Cochlear Implant Summer 2021 Newsletter!

Hello again to all of our patients and their families. We hope that you are all doing well and that you enjoyed reading the first issue of our newsletter last summer. This edition aims to provide an update regarding various aspects of our service.

If you have any suggestions about what content you'd like to see in future newsletters, please let us know! Our contact details can be found below.

**Please note we have a new telephone number.**

We are now seeing patients for routine appointments. If you would like an appointment, please contact us.

### Welcome Kathryn

We would like to take this opportunity to introduce our newest member of our team to you, Kathryn Edge. Kathryn is an experienced Specialist Audiologist and she has joined the Auditory Implant Team on a secondment from the Adult Audiology team here at Glan Clwyd Hospital. I am sure a lot of you will meet Kathryn at some point but here Kathryn will tell you a little bit about herself:



"Working in audiology for the past 18 years I have always enjoyed my work supporting people with hearing loss. Being part of the Adult Rehabilitation Team means I have predominantly been involved in the fitting and management of hearing aids. When the opportunity to train and work within the Auditory Implant Team arose, I was really excited to get involved and start a new challenge. The training and support I have had from the other team members has been fantastic (although COVID has provided some challenges along the way!) and I look forward to meeting you all at some point!"

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### How to Contact Us

**Phone:** 01745 448788 ext. 6061

**Text:** 07557312522

**Email:**  
[BCU.CochlearImplantEnquiries@wales.nhs.uk](mailto:BCU.CochlearImplantEnquiries@wales.nhs.uk)

**Post:** Audiology  
Department, Glan Clwyd  
Hospital, Bodelwyddan,  
Denbighshire, LL18 5UJ

## Patient Participation Group—Call for Volunteers



Here at the North Wales Auditory Implant Programme we have always been very interested in getting feedback from you, our service users, on the services we provide. Given the current situation and the huge amount of changes and developments that have happened in healthcare over the past year this is now more important than ever.

In order to hear your views and get your feedback we are looking to set up a Patient Participation Group. The aim of the group would be to represent the views of cochlear implant users in response to any changes or developments we introduce to our service. This will allow us to 'test' the changes or developments on a group of service users and get your feedback prior to its implementation. Your input will enable us as a service to make sure we are making the correct changes and developing the service appropriately in order to meet our service users' needs. Here are some examples of what we would ask the group to do:

- ◆ Proof read new patient information
- ◆ Give feedback on new developments happening in the service e.g. use of remote care
- ◆ Let us know what you think is good, bad or can be improved about our current service
- ◆ Contribute to ideas about potential clinical research opportunities
- ◆ Provide feedback on our website pages
- ◆ Act as representatives of our service users

We would hope to hold regular catch up meetings with this group whenever we have any tasks that require the group's input. Contact would be made via email, video call or in a face to face meeting when this is allowed. There is no commitment to join every meeting and the majority of communication is envisaged to be done over email.

Your contribution will be extremely valuable to us so if you would be interested in joining the group or would like to know more please let us know.

If you would like to volunteer to be part of this group please send us an email to [BCU.CochlearImplantEnquiries@wales.nhs.uk](mailto:BCU.CochlearImplantEnquiries@wales.nhs.uk) with a brief summary of why you would like to be involved in the group and we will get back to you shortly.

If you don't have access to email but would like to be part of the group, please do still let us know as this will not limit your ability to volunteer.

Thank you, Linor Llwyd Jones  
Clinical Lead (Adult Cochlear Implants)

## Could you tell your story?

When first referred for a Cochlear Implant at North Wales Auditory Implant Programme, we send a booklet out called “So what's it actually like having a cochlear implant? The experience of adults” which outlines patients’ experiences of having a CI across the UK. We thought that it would be nice to have our own collection of stories from our CI recipients. These stories can then be used to share with others considering implantation, highlighting the realities of living with a CI and giving an insight into what to expect!

### What are Patient Stories?

Patient stories are simply a short written/filmed account in which you tell us about your cochlear experience in your own words. There is no set format for the story but previous stories have included length of hearing loss before CI and the effect of this, how you found the CI assessment process, how you managed with the operation and the switch on, as well as benefits and ongoing issues following implantation.

### Can someone else give their perspective of things?

Having a CI is a significant journey in a person’s life and this has an effect on significant others in your life such as family and friends. Should they feel that they would like to contribute to the storytelling alongside you, then this is fine with your permission.

Would you be interested in sharing your story with us? If so, please get in touch with us and we can provide more information!



**A very big thank you to all  
who have already contributed  
their stories to help others!**

## Bimodal Hearing

**Bimodal hearing = use of a cochlear implant in one ear and a hearing aid in the other ear**

In recent years more and more patients are wearing a hearing aid alongside their cochlear implant if they have sufficient hearing in the other ear. There

has been significant research on the benefits of bimodal hearing in the last 10 years and some of the reported benefits include improved localisation of sounds, improved speech perception in quiet and in noise, and better music perception.

At the North Wales Auditory Implant Centre we offer you the choice of keeping your hearing aid care with your original Audiology department or alternatively you can transfer your hearing aid care to our team.

All four cochlear implant manufacturers have now either partnered up with a specific hearing aid manufacturer or have developed assistive listening devices that can be used with their cochlear implant and a hearing aid. There have been significant developments in hearing aid technology recently with new features such as Bluetooth connectivity,

remote assistance technology and compatible apps to control hearing aids on mobile devices.

The majority of our patients are fitted with a Cochlear™ implant and Cochlear have partnered up with GN Resound to work on their bimodal systems. GN Resound have just launched their newest hearing aid model, the Ambio Smart, which allows direct Bluetooth streaming. This means that Nucleus 7 or Kanso 2 cochlear implant users with the Nucleus Smart app can now enjoy bimodal direct streaming to both their cochlear implant and hearing aid should they be fitted with a Ambio Smart hearing aid. You will also be able to control your Ambio Smart hearing aid from your Cochlear Nucleus Smart app on your phone (if supported). We are hoping to get a stock of these hearing aids soon, so if you feel you would benefit from bimodal direct streaming please let us know.

For users of Med-el cochlear implants, they have decided not to partner up with a specific hearing aid manufacturer but to rather ensure that cochlear implant users can carry on using any hearing aid whilst wearing their cochlear implant. The hearing aid details can be added into the Med-el fitting software so that this is taken into account when it comes to programming your cochlear implant meaning that the hearing aid features are considered alongside your cochlear implant.

If you would like to discuss your bimodal options with us please contact us.



Image taken from [www.cochlear.com](http://www.cochlear.com)

## Introducing our new Virtual User Group

Most of you may be aware that prior to the COVID 19 pandemic, the North Wales Auditory Implant programme supported monthly user group meetings at Bodelwyddan, Wrexham and Aintree. The groups were well attended and provided the perfect opportunity for patients undergoing cochlear implant assessment, as well as existing cochlear implant recipients, to meet, socialise and share their experiences. Unfortunately since March 2020 the groups have been unable to meet.

In August 2020, we contacted those who visited the groups regularly and invited them to take part in some trial virtual groups. Since then we have successfully delivered three webinar-style meetings. Elaine Beavan and Susan Boon met with the members online and provided information on communication strategies, online resources and local support services using Microsoft Teams.

The meetings were well attended and feedback suggested that the meetings were easy to access and the information was interesting. Due to the success of these trial virtual meetings we have decided to support a quarterly virtual group and have invited a guest speaker for our next meeting.

Nicole Da Rocha of Advanced Bionics has kindly agreed to speak at our first official virtual cochlear implant group which is due to be held on **Monday 19<sup>th</sup> July at 10am.**

Nicole is passionate about communication and would like to talk to you about the fantastic, free rehabilitation resources that have been developed online by Advanced Bionics.

The meetings are easy to attend and can be accessed via most smartphones, laptops, computers and tablets. For those new to the world of virtual meetings, we have developed step by step guides on how to access and use Microsoft Teams. For those with compatible sound processors, the meetings can be streamed using wireless or direct audio streaming.

We would like to take this opportunity to invite you, your friends and your family to our first official virtual group and really hope you can join us.

Following this, the next group will be held on **Monday 4<sup>th</sup> October at 10am.** Joanne Goss has kindly agreed to provide a talk about tinnitus to the group.

Please contact Susan Boon via email at [BCU.CochlearImplantEnquiries@wales.nhs.uk](mailto:BCU.CochlearImplantEnquiries@wales.nhs.uk) if you would like to attend either of the groups. Details of how to join the meetings will be provided with your invite.





## British Cochlear Implant Group Conference Update



**British  
Cochlear  
Implant  
Group**

Due to the pandemic, the annual BCIG meeting in 2021 was held online. I had the privilege to chair the conference, ably assisted by a committee of CI professionals from around the UK. Our theme was 'Fit for the Future' and we learned about fascinating new technologies on the horizon like gene therapy for deafness

and vestibular implants. One highlight was a performance by the Chester-based Dee Sign Choir, featuring some of our very own CI recipients! They performed a moving rendition of 'This Is Me', which went down a storm with the conference delegates. Linor Jones and Susan Boon also presented at the parallel 'CI Champions' day, which aims to help teams working in hearing aid departments better identify and support possible CI candidates towards referral for a CI.

Next year the BCIG conference is coming home to Wales! The conference will be held in the Town Hall in Cardiff in April 2022, and will be organised by a joint committee from the North and South Wales Implant programmes, chaired by our very own Rebecca Anderson.

We would love to hear your thoughts on what you think cochlear implant professionals should be discussing at events like this. What changes would you like to see to improve your lives over the coming years? Do you have any burning questions for us? Send your thoughts to Rebecca via the CI inbox: [BCU.CochlearImplantEnquiries@wales.nhs.uk](mailto:BCU.CochlearImplantEnquiries@wales.nhs.uk)

Jenny Townsend,  
Head of N Wales Auditory Implant Centre

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### Magnet Reminder

Please remember that your magnet should never be too tight. No pain or soreness should be felt, and there should not be any visible redness to the skin. It's very important that your magnet is an appropriate strength, as if it is too tight there is a chance the skin will eventually break down. This can lead to infection and can compromise the implant.

In extreme cases, the implant has to be removed. It's wise to ask a friend or relative to check your scalp every now and then to check for any redness.

If you feel your magnet is too tight, or if you ever experience any pain in the area, please contact us so we can resolve this for you.

