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North Wales
Auditory
Implant Service

North Wales Cochlear Implant Programme

Patient Newsletter

Summer 2020

Celebrating

30

Years



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Welcome to our First Newsletter!

To all of our patients and their families, hello and welcome to the first edition of our newsletter. Given that we are currently living through unprecedented times, we thought that now would be a good time for us to reach out and update you about how our service has changed due to the COVID-19 pandemic. You'll also find some advice about where you can access useful rehabilitation resources.

The other thing to mention is that 2020 marks **30 years** of our Cochlear Implant Programme here in North Wales. We had planned to have a big celebration, but in the absence of that, this newsletter will take a look back at the last 30 years. We have exciting feature articles from members of our team—past and present—as well as a special article about our very first cochlear implant recipient in 1990.

How to Contact Us

Although we aren't running our usual service at the moment, we are still here and you can contact us in your preferred manner. Please do get in touch with any queries; whether you need support, spares, repairs or anything else!

Phone: 01745 448740 ext. 6061

Text: 07557312522

Email: Cochlear.Implant-Enquiries@wales.nhs.uk

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

North Wales Cochlear Implant Programme— The Early Years

Maire Doran was the first co-ordinator of the North Wales Cochlear Implant Programme and now works for Cochlear Europe Ltd. supporting hearing implant clinics in Wales and Ireland.

My first memory of cochlear implants in North Wales was in 1989 as a (young) Medical Physicist joining a multi-disciplinary team to make cochlear implantation a reality for the first patient implanted in Wales—more on his story later in this edition! Stories were told about ‘back of an envelope’ calculations and corridor conversations to secure funding for this first case. I remember press conferences and a viewing room in theatres for invited surgeons and audiologists. We used a large home video camera and I spent hours taping cables to floors and setting up TV screens, a far cry from current technology.

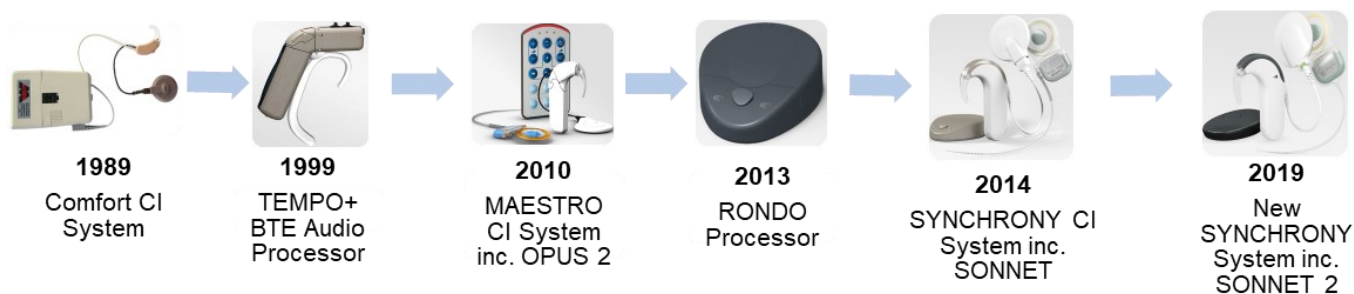
In 1995 there was a national funding agreement for 4 patients a year; demand increased, eligibility criteria changed and technology improved, we now had a waiting list. In 1998 patients from England travelled across the border to avail of this flagship service. There was a hiccup in 2005/06 when Wales temporarily stopped funding cochlear implants; but patients and professionals rallied together with support from RNID Wales to raise the profile of these devices and secure new funding for 12 patients per year. It is great to see how cochlear implants are now accepted as a standard of care in Wales.

Funding isn’t the only thing to have changed from the early years. Technology has also changed beyond recognition, surgery is quicker, eligibility has increased and we have a much better understanding of what implants can do for people. Assessment used to take up to 12 months and was only available to someone with bilateral profound to total deafness. Surgery took 3 hours and patients stayed on the ward for a week recovering. There was a very large incision which required shaving half the head (most people opted for a full head shave). We had a personal wig service provided on the ward.

Switch-on would take place 4 weeks after surgery when patients came back on the ward for a 2 week stay. They were minor celebrities on the ward and always got a private room with TV and subtitles, everyone was excited to see how they got on, from ward staff to the chief exec. They would come down to Audiology twice a day for tuning and rehab. Only one or two electrodes could be switched on each day to give a very gradual introduction to new sounds. We loved hearing a story about every new sound. Did we know that running water made a noise? And throwing cutlery into a drawer could be painful? Rehab took many forms including scrunching up paper and taking walks around the hospital grounds. Everyone had a story and we were privileged to hear them all.

We started off with body worn speech processors, some ladies making pouches to match their dresses whilst others found more unconventional storage places! Ear-level processors were a huge improvement, not just in size but also performance. When S4C televised a live switch-on of our first Esprit24 processor, the immediate result was so good we had letters and calls from existing patients asking if we’d brought in an actor for the TV! That’s how dramatically the technology had improved, and it continues to do so.

The early days of Cochlear Implants in North Wales were such a special time and it has been an amazing experience watching the Cochlear family grow and develop over the years.



Chris Williams: North Wales' First Cochlear Implant Recipient

Josh Williams is the nephew of Chris Williams, North Wales' first cochlear implantee. His uncle's story inspired Josh to become an Audiologist and he now works in the same hospital where Chris received his implant in 1990. He tells us about Chris' journey to hearing:

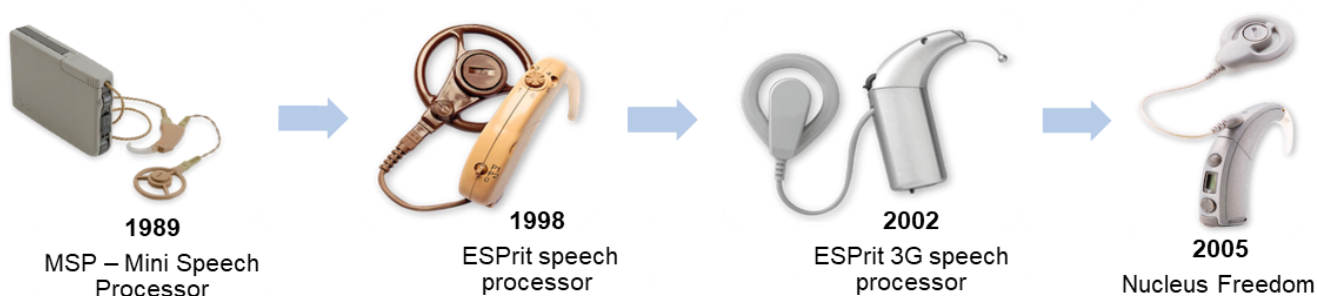
It's been 30 years since Chris was implanted and what he achieved afterwards was truly remarkable. Chris started to lose his hearing at eight years of age after contracting measles. By the age of 21, he had lost all hearing capabilities. Chris was an excellent lip reader, and as long as you were looking at him, you would have assumed he had normal hearing. Throughout school, Chris had a difficult and challenging time as we know children can be cruel. Unfortunately for Chris he was not suitable for a Deaf school and he struggled in grammar school as he was offered no additional support.

An enthusiastic scientist, Chris always wanted to be a researcher and loved to observe chemical reactions. He completed his O Levels, achieved good grades and secured a position in a local research firm, however when they found out he was deaf they let him go. Chris later went on to secure a role as an assistant accountant in Chester, but unfortunately was dismissed on the spot for being too deaf, despite disclosing his profound loss when applying. This was a particular hard blow to Chris as it was not based on his ability or lack of qualifications, but on his hearing. The constant knock-backs made Chris more introverted and he started to become depressed, however there was some light at the end of a very dark tunnel. Chris applied to Hotpoint, which was a factory constructing washing machines. He was initially turned down, but with the help of the Deaf Association, he secured a job.

After some consideration, Chris eventually accepted the offer of a cochlear implant from Professor John Osborne, feeling that he had nothing to lose. Chris spent 11 days in total at the hospital and documented how he felt daily, which was an interesting read. To summarise, he was excited and nervous, but when it came to the shaving of his head, reality set in. Post-surgery he awoke with a terrible pain in his head and found basic tasks like eating, drinking and even brushing his teeth very painful. He wondered if he'd ever recover or leave the hospital.

Chris went through an intense rehabilitation programme where he was instructed to listen to recordings and audiobooks to re-train the brain to fully understand speech and how words are pronounced. He also attended numerous tuning appointments and follow-ups to check on his progress. Initially it was difficult, but with perseverance and support he began to hear sounds and words, and eventually engage in conversations. He was amazed that he was able to hear the busy workings of the shop floor at his job in the Hotpoint factory.

After having the implant, Chris wanted to help other potential cochlear implant candidates and was asked by Glan Clwyd to discuss his experience and the changes it made to his



life. Being able to communicate with others started to bring Chris out of his shell and day by day his confidence grew. Chris really enjoyed this aspect and began a degree at Manchester University, which he successfully completed and became a lecturer in lip reading. Chris was able to share his experiences and expertise of lip reading as well as British Sign Language (BSL).

Unfortunately, Chris passed away at the age of 49 after developing a rare type of liver cancer. Many letters and cards came sending their condolences and also congratulating his mum Jessie on what a wonderful man Chris was. Many commented on how he helped them understand the process of cochlear implantation and how he had helped them with lip-reading in his lectures. Chris had wonderful sense of humour and I believe one comment from a student was “we’ll miss his bad joke at the end of a lecture” - this was a trademark of Chris’.



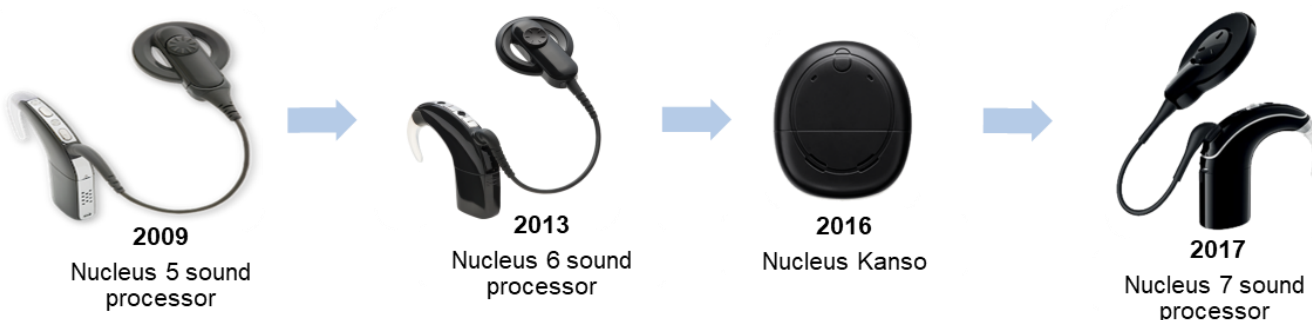
Our CI Journey Continues... A Decade of Change

Jenny Townsend, Clinical Scientist and current Head of the North Wales Auditory Implant Service, talks about some of the highlights of the last 10 years of cochlear implants in North Wales.

In the last few years, the pace of change in the world of hearing implants has really picked up, as I’m sure many of our more seasoned CI users will have experienced directly. As we charge ahead into a whole new ‘post-COVID’ era of change it’s worth reflecting (in no particular order) on how some of these developments have benefitted people with implants, and looking ahead to what might be coming next...

Tackling the last great challenge - speech in noise – with the triumphant arrival of **wireless technology**. What fun we have all had learning to download apps, pair devices and understand how to get the best out of ‘mini-mics’, ‘phone clips’ and ‘TV streamers’...! This is one area it is safe to predict will continue to develop at lightning speed; and with the advent of direct streaming it is becoming much simpler to use, even for the most technophobic amongst us. It has been such a pleasure to watch some people pick up the phone again and appreciate music for the first time in years. Farewell telecoils, your time is almost over!

Smarter surgery: since 2017 we have been performing CI surgery as daycase whenever it is clinically safe to do so. This has allowed us to keep our waiting times down and reduced surgery cancellations, as well as allowing people to get home sooner to recover in their own familiar envi-



ronment. We have also introduced 'soft surgery' techniques to try to hang onto residual hearing.

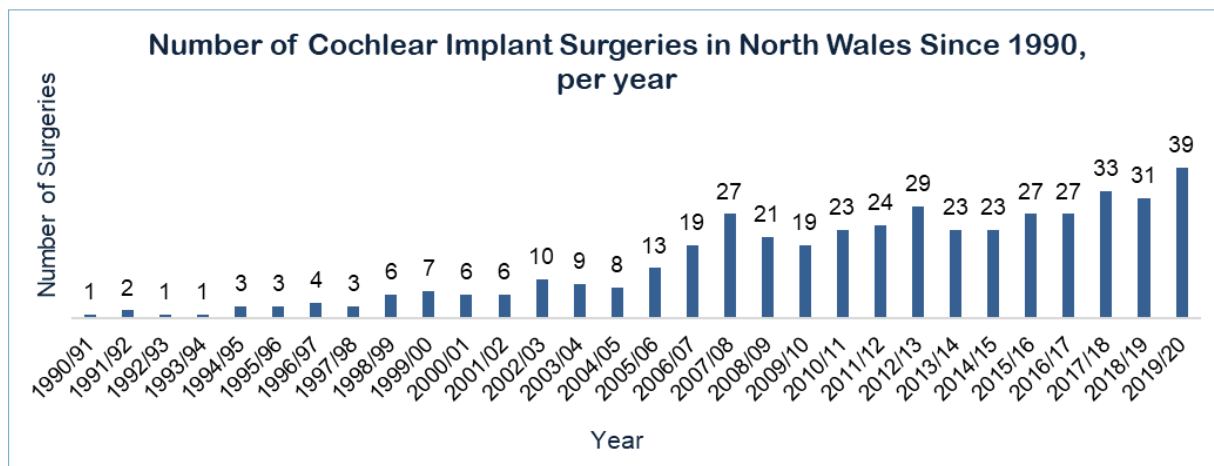
In 2019, the UK CI community won a longstanding campaign to have the **criteria for candidacy** reviewed by NICE. The resulting NICE TA566 (2019) means that many more people with life-altering hearing loss can now access NHS funding for cochlear implantation. Our first recipients implanted under the new criteria are doing well and enjoying the improvement in their hearing!

Over the last few years, a number of new implants have been released with clever new **magnet technology**. These magnets make it much easier and safer to have an MRI scan, without pain and without risk of the internal magnet being moved out of place. Given that the majority of children born today will need at least one MRI scan within their lifetime, these new implants are sure to make a huge difference to the life of children and adults implanted today.

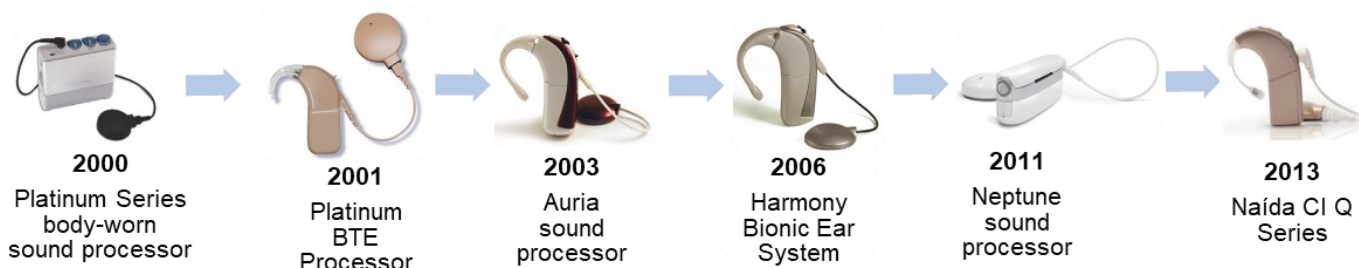
Leaving technology aside, a hugely important feature of the last few years has been the development of our local CI user groups in Aintree and Conwy. Wrexham user group has now been active for over 12 years! We are always being told how valuable these groups are, both for people under assessment and for those continuing on their implant journey. Peer support is truly priceless and we want to thank each and every one of you that contributes by organising or attending these groups, or by helping out with 1:1 peer support by email or in person. Not forgetting all the relatives and friends whose support gives others the confidence to attend, despite their communication challenges.

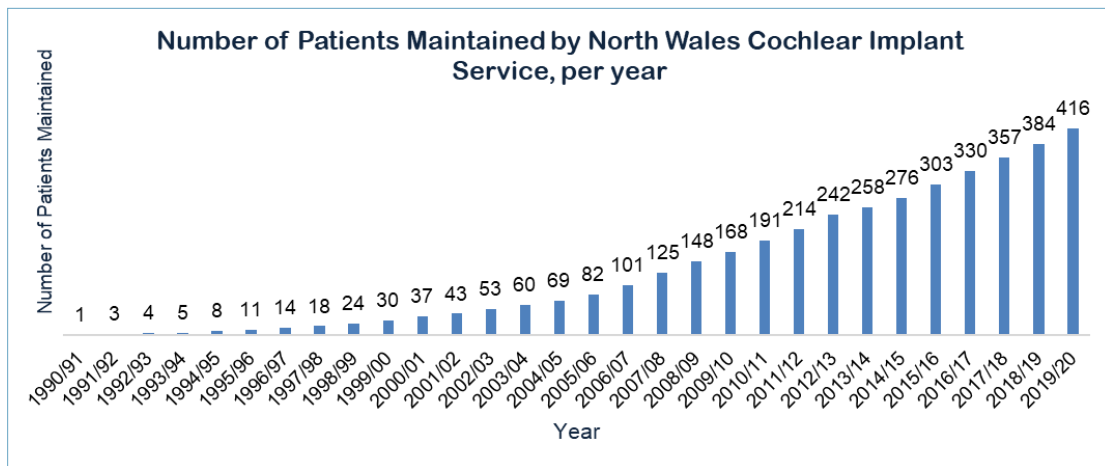
Looking ahead – what will the near future bring for CI users? My predictions: better battery life, more seamless wireless connectivity, and more control in your hands via new and improved apps and remote care options. We have yet to hear anything about Cochlear 'Nucleus 8' or Medel 'Sonnet 3' but I can't wait to find out what they have in store. We do know 'Kanso 2' and 'Rondo 3' are just around the corner... those keen on an off-the-ear solution should watch this space...!

Statistics—Activity Over Time



Total number of surgeries since 1990 = 448



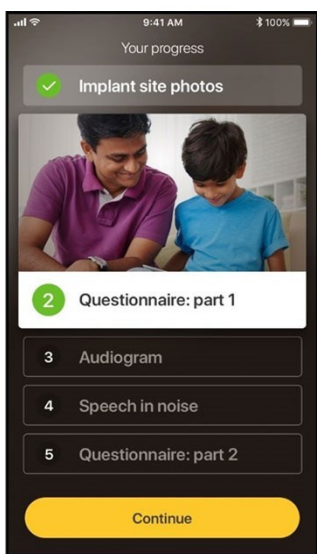


Service Development During COVID-19

The COVID -19 pandemic has resulted in significant changes within many health organisations. We are proud to report that during his time we have worked hard to adapt our service to meet your needs as much as possible, for example developing a remote upgrade service and adapting our rehabilitation service so that it can be provided via video consultation. Where possible we have also been progressing assessments by video consultation. In the near future, Cochlear Remote Check will also become available to some users.

Remote Check

Cochlear Remote Check is a new system that is able to perform some basic CI checks via the Nucleus Smart App. Currently it is only available for patients with a Nucleus 7 processor. A detailed information letter will be sent to patients who are suitable, but it is not compulsory to use. We are keen to be able to offer an equitable service to all of our cochlear implant users, and thus we are also hoping to be able to offer a similar app to all users regardless of type of implant and processor. When this has been established we will be in contact with further detailed information.



Remote Check will provide an overview of the user's hearing health to their audiologist, from the comfort of their home. The audiologist will ask you to complete a few activities via the Smart App. These include photographing the implant site and skin behind your ear, completing two questionnaires, a test that can precisely measure the softest sounds you are able to hear and a listening-in-noise test (to assess your hearing abilities using your cochlear implant). The tool will also check your internal implant using a quick 'impedance test' and perform some hardware checks on your speech processor. Results are then sent via the app to a secure online portal for the audiologist for review; they will get in touch with you if there are any issues that need attention.

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Remote Upgrades

Every five to six years every cochlear implant user at the North Wales Cochlear Implant Service gets offered an upgrade of their current processor, where a suitable newer model exists. This year, due to the COVID-19 restrictions, we had to think of a different way to complete the upgrade process to enable you to get your upgrade in a timely manner and to avoid any delays in benefiting from the most up to date technology.

We decided to test the idea of completing the upgrade remotely. The process involves us ordering the processor kit; once it arrives with us we pre-program the processor with a copy of your most recent settings and then post it on to you at home. When the processor kit arrives, the user opens the package and follows the enclosed instructions on how to set-up the processor and start using it. This is then followed up by a video call review 2 weeks later where the clinician asks about any problems and answers any questions you may have about the new processor.

So far, this process has worked very well for both us and the users who have completed the remote upgrade. User feedback has been very positive. Hopefully it is a more convenient way to receive your upgrade, and for us as a team it means we release time and capacity at our department as we are reducing the number of face to face appointments required. Of course this will never completely take away the need to come in and see us, but it may be an easier way for some people to get their upgrade from now on. If you have received a processor upgrade remotely from us we would be very interested to hear your thoughts!



Online Rehabilitation Resources

Due to the recent lockdown situation and current COVID pandemic, you may have had difficulty accessing different sound environments and experienced less face to face contact with friends and family. Auditory rehabilitation and listening practice are important in helping you achieve maximum success with your cochlear implant, however over the last few months you may have found it difficult to practice.

There are many online rehabilitation programmes that can be accessed via a mobile phone, tablet or computer which you may find useful if you have been struggling to access certain sounds or speech. They can also be used to compliment your existing listening exercises. We have included a small selection from some of the cochlear implant manufacturers although these programmes can be accessed by any cochlear implant recipient and their family and friends. You will find information about these on the next page.





Sound Success, provided by Advanced Bionics at

www.abrehabportal.com, is a useful site which has a selection of free interactive auditory training exercises. The exercises vary in difficulty but can be useful whether you are a new or a more experienced cochlear implant recipient. You will need to create a free personal account to access Sound Success, but this will allow you to record progress and access your account on any smart phone, tablet or computer.



Hear now. And always

Bring Back the Beat, developed by Cochlear, is a fun app which may help you to recognise different types of music and musical instruments. It is free to download on most smart phones and tablets and includes a collection of fun games and listening exercises. For those just returning to music, you may wish to start with identification of different musical notes or instruments, alternatively for more of a challenge, you can link the app to Spotify.



Hear Today is an app created by Medel. It provides information on auditory rehabilitation and also includes listening exercises. The full app is available for a small fee although a free trial or lite version of Hear Today is available to download on most smart phones, tablets or computers. You can also find lots of helpful tips and advice on the Medel website at www.medel.com.

As with all listening practise, some exercises may be more difficult than others. It is important to choose an environment with minimal background noise or distractions but usually with repeated practise they should become easier! Wireless and/or direct audio streaming may also be possible with your processor which may provide increased sound quality.

Please contact a member of the rehabilitation team if you need help choosing an online program or you require assistance with wireless or direct audio streaming.

Over the last few months the rehabilitation team have introduced virtual rehabilitation appointments. If you need help choosing a suitable online rehabilitation programme or require any other rehabilitation support and have access to a smart phone, tablet or computer, we would be happy to arrange a virtual appointment for you.