

**Date:** 7 March 2013  
**Meeting:** Cochlear Implant Talk by Mr Roger Gray  
**Client:** Norfolk Deaf Association  
**Notetaker:** Belinda Sewell

**Please note this record is not verbatim**

## **The Cochlear Implant: Rescue For Profound Deafness**

**Frank Eliel:** Hello and good evening, and thank you for coming. Apologies for the interruption from the original date for the talk due to the snow. Of course, as it happened, the night we were due to hold it the snow had gone but discretion is the better part of valour .....

Welcome and I hope we have a good evening and thank you for supporting the Friends of the NDA event and now I will pass over to Tony Innes, our Chairman, to introduce our speaker and hear something true about him rather than from a C.V.

**Tony Innes:** Thank you so much for coming. I don't know if I can say too many true things about Roger, but we go back a long way, and in the late 70s both he and I were ENT registrars in London and our paths crossed from time to time. We studied for our exams at the same time and had the same tutor, Peter Ellis, senior registrar at University College Hospital - it worked, and Roger and I both fooled the examiners and got our qualifications. Soon after that I came to Norfolk and Roger went to the Royal Free Hospital for a short time and then came to Cambridge.

The Cambridge ENT department has always been good but when Roger joined it was looking up and David Moffat and the same Peter Ellis are both forward-thinking people, and Roger was the same and he joined the department. We are very fortunate having Addenbrookes as a close neighbour and it has earned itself both a national and international reputation for ear surgery and Roger was a part of that and a mover and shaker particularly with regard to cochlear implants, and we will hear more of that later. You can hear the squeaks in the corner from a star patient of Roger's who is here.

I won't go into too much detail but in Norfolk we are very fortunate to have Addenbrookes so close by. Roger does fantastic work and he is a good friend and I'm very pleased he is here tonight. Over to Roger ....

(Applause)

**Mr Roger Gray:** Thank you Tony. Can everyone hear me and I'm standing in the right place? The day I was supposed to come, Cambridge was an ice rink and my children didn't want to go to school so we had to frog march them to school and they were very disgruntled. It was right to postpone.

Let's get going and see if this works. Clayton is helping with the IT so let's see how we go. It would be nice to think that we work in this environment but it's more like this with ENT back of the hospital.

A bit about the structure of the cochlea - I did engineering before medicine which was fortunate as the ear is a great bit of engineering clockwork.

Going through the parts - external ear, canal, the eardrum, three bones of hearing, hammer anvil and stirrup. Behind is the balancing organ and the hearing organ curled into two and three quarter turns and I want to talk about the cochlea today as when it fails hearing aids aren't helpful.

The cochlea structure is hollow with passages for fluid and in the middle chamber is the sense organ itself named after Corti, an Italian. He was the first person to describe the organ of hearing and he got a microscope looked at the inner ear and did drawings. Here is the line of sound sensitive hair cells of which you will hear more, and three lines of outer hair cells. We have 3000 inner hair cells connected to the brain. You may think the eye is a miracle but the ear is the only organ in the body with such a small number of components. When an orchestral conductor tunes up his Orchestra and he has the double basses on the left and Piccolos on the right and says the 2<sup>nd</sup> viola is a bit flat he is probably using 8-9 of the inner hair cells to make that judgement.

Here are the inner and outer hair cells. I have some electron microscopy to show you and these hair cells are multiplied 5000 times. The issue is how robust are they? Can they get damaged and disappear? Of course, as you know, the answer is yes.

I would like to show you a nice video clip from Rockefeller University by Jim Hudsworth.

Here it is, and you see down the ear canal down the drum to the cochlea curled up. It's being straightened out and you will hear some sounds. Different parts of the cochlea vibrate to different pitches/frequencies.

If we can go back to the presentation. Each pitch and frequency vibrates at a different part in the inner ear and the hair cells specific to the pitch or frequency, so it's important that you don't lose any, or you would lose the appreciation of that pitch.

If you look with an electron microscope at a single hair cell and you dance at the front of a disco at age 18 so you vibrate that is what happens to your hair cells and that is noise damage which won't recover if repeated too often.

Here is another picture of a line of hair cells and what happens if the cochlea is damaged and is the cause of sensory hearing loss - noise is just one reason for loss. There is genetics, drugs, wear and tear and infections, many things. It doesn't repair itself.

What can we do about hearing loss? This was the first thing, an ear trumpet which doesn't give any distortion.

Early hearing aids - that says Oticon, and I'm sure some of you wear Scandinavian Oticon hearing aids, and in there is a glass valve as an amplifier.

Have you had your hearing tested in a sound proof booth? That is how hearing is tested. We measure hearing in decibels which is a comparison with a test sound, and all sound is compared to that pressure level.

One more slide - then over to Emily\*.

***\* all family names have been altered to protect their privacy***

This is the classic audiogram - a graph of hearing - top is good and bottom is bad. There are high, middle and low pitches. This person has no sound until 110 decibels - a road drill.

Now I will introduce the Winterton\* family. Andrew\* and Sarah\* have two beautiful children born with hearing losses for no apparent reason, as both parents have normal hearing.

Andrew is standing with Emily who is now 26 months old and has two cochlear implants. I wanted to ask what your thoughts were for your daughters future when she was born profoundly deaf.

**Andrew:** We have no deafness in our family and were very surprised, and we were devastated. We had no experience of deafness, let alone in children. You wait 9 months for your child to arrive and in the next two weeks you hear your child is profoundly deaf. The process is thorough but takes time and as parents you want answers and you have to resign yourself to the process in the hands of capable professionals like Mr Gray but it was very difficult. We spent a lot of time visualising what Emily's\* life would be like, and tried hearing aids.

**Mr Gray:** Did the hearing aid help?

**Andrew\*:** No, not at all. My sister has 6 hearing children and my parents also struggled with this. My father would come up behind Emily\* and slam a door and she would cry from the vibration and he thought she could hear. Norfolk and Norwich increased the gain and sound range that should be available to Emily\* but no response.

We started using sign language thinking that was the only access to communication for Emily\* and didn't know about cochlear implants at that stage. We thought she would not hear music and would be deprived of certain senses Sarah\* and I had, and we went through how we could communicate with Emily\* and we started signing and she responded but felt she would not participate in mainstream schooling and looked into what deaf schools were available locally.

**Mr Gray:** How did you decide on a cochlear implant?

**Andrew\*:** it was a tough decision and we took a long time to consider it and largely our decision was informed by talking to other parents and reading a lot about hair cells and how the cochlea works and balancing the decision in not trying to "fix"

Emily\* and I still get angry with people when they consider her “fixed” as in my mind she was never “broken” in the first place.

**Mr Gray:** How did the operation go and how old was she?

**Andrew\*:** She was 14 months at the time of the operation as you know, and there was a small complication in that we thought it would be a bilateral implant but due to an infection we did one side and then the other after four weeks. We waited for them to settle down and then turned on, as you know better than me, after 6 weeks. The operation itself is - it's a long operation and you are advised by other parents not to watch the operation on the internet but curiosity gets the better of you and it's a long complex operation requiring immense skill.

**Mr Gray:** It gets better with experience. What effect have the implants had on Emily\* and her communication?

**Andrew\*:** She is quite vocal now as you can hear, and it took a while. On the internet there are videos of the implants being switched on and the ones you watch are the ones where you get an immediate reaction but they are all different. We had the video camera out for Emily\* but there was nothing and we wondered if Mr Gray had done anything at all. It took a month before we started seeing Emily\* respond to sound and it never moves quickly enough but in four months, which is a very short time, we got the first words and she has now been switched on for a year and she recognises many words and we have started dropping the sign language now but we will never drop it completely as we want Emily\* to occupy both the hearing and deaf world. We will reinforce it. She is up to her peer group and is very articulate with the word “no” and it surpassed our expectations.

**Mr Gray:** Would you do it again?

**Andrew\*:** We get to do it again as Ben\* is also profoundly deaf and he has been referred to Addenbrookes and he is 10 months old and very young.

**Mr Gray:** I have the instruments in the car

**Andrew\*:** how much have you had to drink?! We would do it again, absolutely, and it's a personal choice and not a choice we have regretted for a second and if there was any doubt it is gone and we will go through the same process for Ben\*. We don't know if the results will be the same as with Emily\* and hearing children vocalise and speak at different stages and we have to handle our expectations for him being a boy.

**Mr Gray:** thank you very much it was wonderful. I don't know if you can see Emily's\* implants. Could you lift her up please and take one off and put it back on so they can see the magnet on the inside of the head with a receiver/transmitter? She has a pair of them.

Thank you and that was wonderful. And so here we are with profound sensory neural deafness beyond the reach of hearing aid and here the neurologists say they have

done all they can, go live with it. That has occurred for decades but now we can bypass the hair cells

Let's see where the pitches are in the cochlea. There are three bass singers, tenors here, altos here and sopranos here to show you the pitch distribution. It's vital, as the wires we put in will rest at those appropriate places. If you put a wire here the brain hears a bass note and through an electrode here it hears a high pitch. It makes it possible to mimic speech through an electrode and its beautifully laid out and almost as if an engineer would come and solve the problem.

We discovered in children with sensory hearing loss in most cases it's a genetic abnormality called *Connexin 26* and we found out they do amazingly well with cochlear implants and we have made significant strides in recent year.

Scientists were doom and gloom and said if nerves died the hair cells would die too but it wasn't true. Some said you could not say that without trying. Brunel said an ounce of experiment is worth a ton of theory and that proved true here.

In France, Djourno and his team were dealing with a horrid disease of the ear and they found the eardrum was gone, and the bones and the cochlea, and they were looking at the stump and they put a wire on it and an electrode on the nerve and connected it to an induction coil and turned the voltage down low and they could hear the sound of crickets and when they changed the wheel the pitch went up and down and you could deliver rhythm if not pitch.

Next we have the major players who did the development of the cochlear implants and there are three stories. Graham Clark trained at Newcastle and went to Melbourne as a ten pound pomme. He researched in 1969 cochlear implants and for a while the Australians had the bionic ear on their stamps and I think it was the first time the Australians ever produced something first!

1969 these were developed - and about 50-60 thousand people in the world have these installed.

San Francisco - Robert Schindler - I went to this man's lab and became involved in a programme for cochlear implants and when I came back there were no implants in Britain and I was in the right place in a receptive hospital and we started a programme here.

The new implant is called the Clarion and called Advanced Bionics and there is a waterproof one too.

Inge Hochmair is the Europe producer in Innsbruck that turns out approximately 50 a month. She was a medical student in Innsbruck University but didn't enjoy medicine. They had a visitor on electro physiological devices and she changed her course to engineering, married the lecturer and Emily\* has this woman's brain child in her head.

We made our own electrodes and put a wire in the ear and asked patients what they could hear. Then, in London a group made the first single channel implant and you

can see the capacitor, resistor and diode - a simple circuit. These two wires were cut off and one is the earth lead and the other went in the cochlea and the patient heard the rhythm of speech which wasn't very informative.

Graham Fraser, John Graham and myself worked in the UK and Graham Fraser was the sensible guy who said we needed funding.

He took a patient with Jack Ashleigh and the health minister gave them £3M to get the programme going, and three centres got the money and started.

How does an implant work? You have an electrode in the cochlea with something like 8-20 separate platinum contacts with a wire to a radio receiver under the scalp. You can't see it but it doesn't work on its own as it doesn't have batteries or a microphone which are on the outside.

This is the speech processor that takes the sound and digitises them and puts the sound into 12 separate bins for different frequencies like the people in the choir and sends the information through a transmitter to the receiver which talks to the electrodes and tells them what to do. The first one does a job and goes to the back and then shuffles forward again. If in silence they keep going to the back of the queue and do nothing but if there is a sound then the electrode is active, before it goes to the back. This happens 15,000 a second and although the sounds are delivered separately because they are so rapid it seems simultaneous, like with pictures.

Now what about famous people that went deaf and their impact. This was Beethoven. He had ringing in the ear. The high pitch went first and by 32 he was profoundly deaf, became depressed and wrote about it.

Ok. A bit of medicine now. How do we know if a patient who is deaf has an organ or nerve of hearing so they can have a cochlear implant? Here we have a magnetic resonance head scan which cuts through the head like slices of bread. This one goes right through the cochlea and here is the balancing organs and there is the nerve of balance and one of hearing. This person could have their hearing restored.

Here the cochlea and nerves aren't distinct. This person had meningitis and the pus went into the cochlea and hair cells and caused inflammation and went hard. There are no passages in the cochlea so it's hard to put in an implant so there are challenges with some types of deafness but it's fairly rare.

This is the device from San Francisco. Here is the cochlea, here is the scout master and aerial and the magnet. Here is the outside part that looks like a hearing aid but doesn't deliver sound to the ear canal. The information goes up the wire to the transmitter coil with a magnet and a stream of information passes from one to the other.

I have a video on an operation but it isn't gory. The patients are covered over and we mark the position of the implant and its vital we get them in the same position.

With children my anxiety is that they come out symmetrical - you have to mark it carefully.

Got a short video here showing you how we drill a tiny hole. We go through the mastoid which is like honeycomb and we are between the round/oval window. What you see here was forbidden for most of my training. We were told if you go into the cochlea you will destroy it so never make a hole in the cochlea. But if it doesn't work anyway there is nothing to lose. It depends on the patient circumstances and happily you can do good here and not harm but it has to be delicately done.

A lot of technology went into this with the best possible electrode and implant. This is curled and you can't push it in but there is a little wire that goes down the middle to hold it out straight and it goes in straight and then you pull the wire out and it curls. The closer you get the more accurate the pitches so you hear the tenors and sopranos separately.

You advance it slowly and it disappears from view and you hope it went into the right place.

Next video.

There is an electrode entering a cochlea and it's in a bone that was thinned down, out of the body, to the point you can see through it and then they video the insertion of the electrode. It's a beautiful structure and answer to the problem in terms of engineering. Here are the three basses, tenors and altos and sopranos.

Now, people often ask "how do you know when you come to switch it on in a very young child if it is loud enough to hear something but not to frighten them through loud sounds?" The answer is electronic tests. The stirrup bone tramps on the oval window like this. Tony, hold my arm. The muscle has tendon attached to the stirrup bone and if you pull my arm I can only stamp with the other foot so it's a protection from very noisy situations and the joy of it is that it works when you switch an implant on.

So we then attach it to a laptop and turns to say, 6, and then we watch the tendon until it moves and then we know the child has experienced a moderately loud sound and we can chart the levels across all the electrodes and so when we switch it on it won't cause problems .

There is a video of this happening. Look closely. The tendon is the smallest muscle in the body and we are putting current on the implant now. See it twitch? and there is one more.

Excitingly for me, with a two year old child, I know the muscle has never contracted until the electrode went in and its remarkable the reflexes are there but may remain unused all the child's life unless you can deliver sound.

Here is someone wearing the speech processor there and there is the cable and transmitter coil. They remove it for swimming and at night. The person still may want

to sign and use BSL and have a foot in both camps because if this fails they still need to be able to communicate.

The vision for children - every child should start school with normal speech and language even if born deaf.

We want to find them at age 1 and implant them at age 2 as there is just a window of 5 years of plasticity and after that it is hard to acquire speech.

We only have two young children in the room and the rest of us are concerned about our hearing going down through life - progressive deafness.

First you can't hear noise, then at home and, if you are unlucky, hearing aids that used to help don't help now and the Audiologist says that is it - now we have cochlear implants though. If you reach the 6<sup>th</sup> spot on this chart then perhaps an implant is for you

What are the limitations of hearing aid? - the Audiologist tries to match the amplification of the hearing aid to the level you desire. In the high frequencies and hearing levels are poor not even the most expensive hearing aid will help. NICE guide doctors and they say anyone that has hearing loss greater than 90 decibels at these frequencies should be considered for a cochlear implant and they pay for it, which is great as these things are about £25K for the operation and rehabilitation.

Here you can't hear the high pitch consonants and it changes your speech.

Here is someone's experience who lost hearing at age 34. The results were extraordinary and Scott recognised 100% of more than 1400 words.

Was it normal hearing and what did it sound like? The electrode array gives a stimulus that is a crude representation and sounds like Steven Hawkin or Donald Duck. For someone that recently went deaf they say synthesised speech but a year later they don't remember what normal speech sounded like but what they have now is normal for them now.

About two thirds of our patients after a year can use the telephone to communicate with someone they don't know.

What does the audiometric chart look like after and before an implant. It isn't up to normal but around 40 decibels and speech is about 60 so the sound comes in here somewhere. People with implants can enjoy understanding of speech if there isn't too much background noise.

What if you are age 30 and a skilled BSL user and were profoundly deaf from childhood and the opportunity for a cochlear implant wasn't available and you missed the boat or the services were not available?

The bad news is that if you have an implant it won't normally give you speech which is very sad as many people would like to solve those problems as would I, but the window for opportunity is the first five years of a child's life.

The good news is that lots of BSL users have some understanding from an early age and in the brain is a type of library and there is something there and anyone with an interest in speech find their understanding of speech is much better after a cochlear implant. So we have changed policy and said it makes a big difference but won't give normal speech.

We have here a PET scan of the brain where if you do a task the part of the brain that is active lights up. This person is listening to speech. On the left is a person with acquired deafness and a cochlear implant and listening to speech and both sides of the brain are active.

This person had hearing loss from birth and is listening with a cochlear implant and there is less activity and there is more activity in the visual cortex which BSL users have.

Now, this is a story of a girl a bit older than Emily\* and I have some video of her at age 3, profoundly deaf and no speech and then video of her at age 11.

She was born in 1995 and the parents suspected deafness and the doctors said she would grow out of it. No speech age 2.5 and she had a cochlear implant age 3.

There are pictures of a birthday cake and a fish. She is being asked to identify them.

This one is birthday cake with candles on it.

Four - birthday cake

**Mr Gray:** She is saying my mum had a birthday.

You have to point to the right one. Fish

**Mr Gray:** She got that one right.

Car, car. Good girl.

Key.

**Mr Gray:** not sure of that one

Key - it's this one. Birthday cake.

**Mr Gray:** You can see how difficult it is and no speech age 3.

Now she is age 11 and her Mother filmed this in her bedroom

"what else do you have that is special"

"I have a special box and it is really good and sometimes it flashes and it tells you the time and you press it again and I get mad with it.

"where do you put your implant at night?"

"I keep it in my tray and ...

**Mr Gray:** Technology lets you down!

“I get my implant and when I go to bed I get this and put it there and like that and then I put it like that...”

**MrGray:** Her speech changes when she takes her implant off.

“My implant is .....”

**Mr Gray:** We will stop there as it's tedious. Ok, interestingly when she removed her implant her speech changed with longer vowels and she could not modulate the loudness of her speech and she said she could not hear with her implant off and she started signing. She has remarkable clear speech for someone who could not say anything at age 3.

Is this the end of childhood deafness? Screening is becoming universal using a little box and cochlear implants should be offered at age 1.

An Audiologist presses a button and if there are hair cells you get an echo but you won't if there are no hair cells. Children are tested very early. I used to get children coming at age 3 and deafness had not been diagnosed when the child wasn't speaking. If its sensory neural deafness you have lost 3 years when they would be learning ten new words daily.

There is an x-ray of a cochlea in position with the electrode in there.

There has been some opposition to cochlear implants and a leading surgeon in America said they could change fundamentally how deaf people live and they have changed their position. One University in America has all deaf students, teachers, professors etc. They said it was “hearingism” and would not have it. Some professors then crept off and had cochlear implants and made their life easier and now cochlear implants are acceptable at that University and that has changed the policy universally.

At Addenbrookes we now have 4 ENT surgeons whose passion is putting electrodes in the cochlea and we have rehabilitation people and are up to 1200 patients and 480 are children.

There are other implants and these are for people whose eardrum and middle ears are on the scrap heap and I'm pleased to say the technology is skilfully practised in Norwich so a wide range of hearing disorders can be fixed in Norwich but if it's the cochlea you have to come to Cambridge

When Emily's\* implants wear out or are changed she will get TICI which has nothing on the outside of the head.

You have a rechargeable battery by lying on the coil at night on the pillow and it charges the implant. How many times can you do that though? They have extrapolated and they reckon the battery will produce 8 hours of use for 16 years and that solves the ethical issues.

What to do with the microphone. Under the skin it can hear heartbeat and rustle of hats etc. the next thing is to clip it to the little bone of hearing and it won't be long until it will be totally inserted which is astounding.

That is it!

Applause

Any questions?

Question: You have got 20 electrodes - I'm curious if people sense the harmonics. Or do you know about that and how people experience them.

**Mr Gray:** They do as if you test with a single note they hear that and if you take a cello they hear several notes to activate several electrodes. They can tell it isn't a single tone.

Question: You have three centres in London Manchester and Cambridge - do you need more to meet the demand for children like Emily\* and Ben\*?

**Mr Gray:** You are right and we now have 23 centres as the major hospitals have started implant programmes. 12 do young children

Question: Will Emily\* need her implant changed?

**Mr Gray:** The manufacturer say they are good for 70 years but we don't believe them and have a 5% replacement rate because they have broken. The joy is that if you have had one for 20 years and they break there are tears but then you are pleased you can have an updated one and it can just lie in the bed of the first one and works just as well and the new electrodes mean they work better. We are just beginning to think how many Emily\* may need and designing the electrode to be the least traumatic and working away from the curly one to avoid rasping the cochlea.

Question: I haven't been able to hear music and yet I can hear voices.

**Mr Gray:** Do you have a cochlear implant? Yes. The speech processor is designed to take sound and turn it into speech. Companies are working on programmes so you can enjoy music.

Comment: I don't understand why I can't hear music as I can hear voices going up and down. I have the Nucleus implant

**Mr Gray:** the nucleus electrode stops two thirds of the way up which is needed for speech but musical instruments are distributed at the top where your implant doesn't reach.

Question: How often is balance affected after the operation.

**Mr Gray:** You are right. You assault the balancing organ too in an operation as they share the same fluid. There are new techniques to preserve the fluid in the inner ear and if done carefully with steroids then the balance can be saved but people have had balance loss which normally recovers. You lose balance as the fluid comes out

and normally replaces itself in a week. If not, then it hasn't like the implant pushed in and we are changing our strategies to avoid that happening.

**Tony Innes:** Some months ago the idea for this speech was being formalised and I was asked if this Mr Gray was any good. I said "just wait and see!"

When I talked to Roger about the audience I said it would mostly be a lay (non medical) audience. There would be some people with first-hand experience of cochlear implants and a greater number of people who have significant deafness or have family members affected by deafness. Roger said he had never really lectured to a lay audience before and all I can say is "you would never guess would you?" I think he has been a tour de force so thank you very much Roger.

**Mr Gray:** Can we thank Belinda too. Thank you and Clayton for the IT who spent an hour getting this to work!

**Frank Eliel:** Thank you for being here and I have several Thank Yous later. It's interesting how many people are affected by these things. My mother took medicine in her 60s and then went profoundly deaf and I remember clapping behind my mother and not believing she could not hear and she would not lock her front door but would never know if someone was in her house. She was offered a cochlear implant at age 80 but didn't go ahead and I didn't see the benefit she may have had.

I joined the NDA and helped setting up the Friends of the NDA and as with others we have problems in getting the money coming in for the charity work we want to do and we thought if we got a good number of people who recognise the benefit we may get more members and we have got to 250 but it isn't enough for a big financial difference. We want to broaden what we do and are looking for new ideas and for new committee members to discuss our activities. This is the 2<sup>nd</sup> talk we have done and hope they are regular occurrences as they have both been fantastic.

We have Theatre Royal connections and we are going to a captioned performance at the theatre. That facility was brought in for operas and it can be used for any other show now. We were hoping to go to Starlight Express but due to an administration problem that isn't happening but we are going to Evita and it will be good seats and with nibbles on Friday 27<sup>th</sup> July at 7.30 so if you are interested in that event talk to the NDA office and get your tickets.

We want to run other events like that and are trying to make connections with Cinemas too as we don't get the warnings in advance of subtitled performances.

Please join and get other people that could be members to join and take away leaflets as this great organisation always needs support.

Thank you Roger, super stuff and an unknown world but it was made comprehensible to me and thank you (to Emily\* and Ben's\* parents) for coming and sharing your children

Applause

And well done and you should clap yourself as its boring at your age.

Thank you to the notetaker and Clayton and Aliona and her team for the food organising and to Jarrolds for the facility. Thank you to two companies who have made money available to defray the cost and then the money we put in goes right back to the NDA, Cozens-Hardy and M & A Partners.

Now I should offer Roger a small vote of thanks. No surprise what is in here! (A bottle)

Thank you again and safe journey home and look forward to seeing you at the next event.

**Tony Innes:** Thank you again to Emily\* and Ben\* and their parents. We can all see that Ben\* isn't "broken" either but we wish you all the best. You are in very good hands.

**End**