

Rough Edited Copy

Cochlear Americas  
CA-CAN Chapter Meeting  
April 9, 2016

CAPTIONING PROVIDED BY:  
ALTERNATIVE COMMUNICATION SERVICES, LLC  
P.O. BOX 278  
LOMBARD, IL

\*\*\*\*\*

This is being provided in a rough-draft format. Communication Access Real-time Translation (CART) is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings.

\*\*\*\*\*

Dr. Samy is here. How many of you know him

The most personal ear doctor I have met

A Golf outing sponsored by UC. Info up on front table.

You noticed a lot of furniture downstairs. If you look and see something you like.

I will turn it over to Dr. Samy.

Dr. Samy: It is a pleasure to be here. I have been in Cincinnati over a decade. Things have changed. I came in 2005.

It took time and education and this group is a huge part of that.

I have patients 70 that would never think of implants.

Things are changing.

Quality of life is important.

I have older parents. It is hard to see my parents get older.

I have older parents. They both fought hearing aids off.

My mom was worse and worse in social situation. A lot of evidence that hearing loss can contribute to depression.

The way god has designed our brains.

One thing to realize, research and implantation

Neuroplasticity. How you brain responds

I gave a talk Thursday at UC and this is a group at UC former doctors and current medical students

I was surprised how few new about cochlear implants.

My goal is from you to see what you think.

There were people in Australia implanted with nothing external.

I went to a meeting a few years ago and it was amazing to see.

How do you deal with battery life.

When you turn your head they could hear their scalp move. Nothing external.

They love the device.

The most important question:

A few research topics we are working on:

Our skill are finite. Some of the tools reduce damage.

In the 80's if you put the electrode in very delicately maybe people have less problems

Maybe the hybrid device.

The lasers that help

We are starting single sided deafness.

Maybe a virus or car accident

For years we thought on good ear leave it alone.

Now we are looking at single sided implants.

About 20 patients implanted.

I am realizing some of them struggling for a different reason

Some have tinnitus.

Ringling in the ear.

They are struggling.

We are working with John Clark to see if there is better way to educate patients.

If don't meet patient's expectations we have done a disservice

I was so excited and I don't think I counseled them well  
This is not something you want to rush into until you are  
ready

I don't want it to be felt that doctors are pushing it.

Sheree is someone I work with and she loves the  
cochlear implant.

She was curious why she didn't see African Americans  
with cochlear implants.

Other ethnicities also

I have crated out own website.

Please visit that

I will put this on it today

I want people to realize the Cochlear implant society is  
big in Cincinnati

A few years ago I had a patient implanted.

Went to her primary doctor for vaccinations.

The doctor said you have to go to California for the surgery

This was just a few years ago.

Go to this website.

I feel this group is strong advocate for CI

What is the biggest problem you have

I had my implant since 2011. From my first activation.

For some –

It was too high.

Last time we did right side and I keep telling her to raise  
the volume

I don't know how to deal with it I want to hear more.

I am not an audiologist. There is a level of sound. As current goes up risking damage

Laurel: the battery could have issues. Decrease in battery life.

With maps we have one battery to work with

She can stand up front.

When we map cochlear implant we are limited by the battery

We have limitations

Brian wants volume up . we cannot support. The more wide we make it the more the current –

Rechargeable?

It is not power the load is too great

What is downside?

You go too wide you have smearing. We need it a little more narrow.

I don't know where you are now

Typically the pulse width is not adjusted

You can adjust so battery doesn't decrease as much

Intermittency is issue.

It can be caused by a lot of things. I could also be a mapping issue

Require surgery?

No

Where is the battery?

We will cover that later.

This is the battery

My name is Deb

My biggest problem is this is not long enough to fit behind the ear.

She tells me exactly what she thinks

When did Brian start having hearing loss

Got my first hearing aid in Kindergarten, second in college

So when we are born we hear sound

Hearing loss is number one birth defect

We have a hearing screening at birth

Babies are tested right away

One out of a thousand has profound hearing loss.

Other children have ear issues cause hearing loss

Then adults having hearing loss

There is data—

If you get hearing loss right away. My youngest I implanted was 10 months, oldest 92

If by age of 5 the brain is not stimulated by sound they can lose ability.

I am noticing I have more patients now grew up with hearing loss and interested in CI

I implanted a man that did sign language and wanted CI

He said just wanted to hear children

Meeting patients expectations. He just wanted to hear something

My hardest thing dealing with the high tones because I have not heard them in 25 years. I have beeps etc., I am

early on but the high tones are screeching at me

I was implanted about 4 years.

My family history, mine was progressive from 20s we did  
my left side

My hardest thing is phones. I still have issues. Depends  
on the person on the other end

I have gotten better in the last year.

They say music is hard to enjoy again

God knew I needed my music

I thank God every day for people like Dr. Samy

You withdraw form situations because you don't want  
people to think you are weird.

I thank God for Dr. Samy

I have a cochlear implant

I have to backtrack my condition can be increased by  
stress.

I was shopping one day and could not hear

I thought battery died... the hearing aid was fine.

My hearing dropped like that because of stress.

I had nothing on my left side I had nothing on this side, I  
ended up with him. I should have done it sooner

That is a question you ask yourself

How long did it take to adjust to hearing

The day I was activated I went from 30 to 90 percent  
comprehension.

Everyone is different

My sister has bilateral implants and I had a roar and

asked her about it

It takes time it is a process

You have to work with it

My daughter noticed the difference with a month

I can have a conversation with her now

After Dr. Samy's presentation we will break up into groups

for questions

This is my biggest question:

How do you deal with the costs

Second implant

Accessories

We have research areas—3 FDA approved.

How do you deal with the cost of this?

I was implanted. I am retired and on Medicare

advantage care

The takeover for Social security only copay of 240 dollars

One of the frustration.

I am in medicine and I don't understand hospital bills.

I have a few patients self-pay. A small percentage

The hospital is trying to flat fee probable 30 to 35

thousand total

The bill was way over 100,000

Medicare pays way less. The hospital loses money on the

device

Medicare does ok. The commercial payers pay 30 to 35

thousand

This is a big deal



Several groups had to stop doing implant and some limit how many they can do a year

There are millions of people that could benefit

300,000 have implants and millions need

Those in implant industry need to know what is keeping us lower recipients

If I have 100 people in a room what percentage get implant that need it?

Only 6%

That is low

I had my first 6 years ago. I spent 200, I had good insurance

I had second with Medicare hospital bill over 200,000

Your bill was denied. You appealed it. I was not responsible. I feel guilty, you should be paid for work you did

We are caught in insurance

Doctors and hospitals know they will not get full amount

I brought my bill to audiologist

Charges were crazy

You know if you see the bill

You are charged for everything and it looks redundant

I am a nurse.

Something has to be done

People are denied services because of cost

I just want to say I had CI in 2000

My doctor had trouble with my insurance it took 30 days

of letters etc. to convince insurance

Took 30 days for insurance to cover it.

They covered whole surgery

I don't know what insurance is doing now

I have had upgrades

I went on Medicare and only paid 1500 for upgrade

Now trying to get nucleus 6

Not to belabor the point but look into your coverage

I have a great team and could not do without them

It is an honor to work with them

It takes a village to keep me going

One of my goals is to approve a patient with in 30 day

One way you can help is check

I called my insurance company and they had all these terminologies and depends on codes etc...

I have no idea

You communicating with Sheree will help

Sheree Sims

If you think of things to ask I can give her email

People on Medicare, do you know if they will pay for batteries

I am on worker's comp and they have a special department the will work with Medicare and worker's comp to get batteries paid for—cochlear helps

I just called cochlear and—reimbursement department

We are trying to get all 3 companies to respond to patients

We have patients that drive a long way

We are looking at having maps in the cloud so it can be sent to local audiologists

I go to India once a year to do implants

Maps in the cloud is important

The companies are getting much better but need feedback

Any other issues with fit

It takes a while to get used to it especially with glasses too

Be patient, you will get used to it

Discomfort is normal, pain is not

If you have pain, I had patients, the device feels like it will push through the skin, not common

Things we need to do to adjust

I went to get new glasses, the thinner ones work better

In early state of cochlear, it hurt

The first time I had a little hole, the battery was too strong and we put in lesser battery and it went away

If there is pain there is a cause

I needed a less strong battery

She said batter she was talking magnet

I had mine not quite a year and a half

How many get better over time

It used to be we thought a plateau effect with adults

Studies show as an adult you can continue to improve up to 3 years

Earlier we were talking about Tinnitus

How many people hated the device the day it was  
implanted

I have done about 400 implants. Some hate the sound at  
first and stop using the device

The answer is years out you can get better and better

Brian, how do you feel?

A couple ways I adjust to my implant

I used my remote today to hear better

Last night I was in loud restaurant

I could have an adjusted but after a few minutes I can hear

It is an adjustment my brain makes

2 ways the hearing can change

The remote and you brain adjusting

Your brain can make hearing better

If you pay a lot of attention to music that helps with  
music

How do you do with speech quiet?

Music. A researcher I work with there is data that shows  
music training may make you better with speech

Stimulating the brain with classical music

Maybe learning a foreign language may make you better

It is up to you to grow and be the best possible

Before my implant I could not understand music

After implant I could hear instead of lip reading

As far as music, after about 6 months I could understand  
people on the radio in my car

Music is still a little complicated, but I can hear some

words melodies are still a little complicated.

Remind me, who in here had an implant, raise your  
hands

All doing well with speech quiet environment

Noisy environments

Music?

The hardware improvements are better and better

We do clinicals at UC

Noisy and music are issues

I go to gym and program and I can tell the instruments  
now

I can understand the radio now

I use the wireless clip with iPod

I use the telephone one it programs with Bluetooth

While I was in training with CI

I didn't want to get out of the car

The phone rang and I answered and I could hear. Now I  
am hearing on the phone

With the mic, Bluetooth

Bluetooth is better feature?

I am just activated for a month

Not knowing who it is

The voices sound alike

I can hear but don't know who it is

It gets better

I have only been a month

I don't have Bluetooth, I do fine

How do we let patients know things changing? How do we get info to patients

Vaccines

Meningitis is a small risk

When we first started no one thought about vaccines

Now we are requiring 2 vaccines

Everyone aware of that

It reduces pneumonia and meningitis

Pneumonia vaccine-- - a year apart

In 15 years I have not had a single meningitis

Both need to be done within a year

Risks of facial nerve injury a 1%

She having surgery in 2 weeks getting vaccines

I am not a stickler, the risk of them is 1% never had a single patient but get both done, I am okay with it

I was born deaf, when I had surgery never had vaccines

12 years ago

Now you need them for the second one

12 years ago we didn't know about

There were cases of meningitis, so we now get vaccines

I have a Baha, do I need vaccines?

No just CI

What do you do or not do because of CI

I avoid swimming I limits activities

So much you with you didn't get it

No I would rather hear

You know you can take it off to swim

I have aqua plus—swim suit for regular cochlear implant

I can use the mini mic and swim at the lake

I don't think aqua accessory for Baha

I have freedom CI I like to roller skate

No limits.

If I swim I take it off

Some of these we addressed

All of you I guess adjust

Does anyone avoid certain situations

I avoid some places because of acoustics with the Baha I

cannot make adjustments

Deb, how long did it take you

3 to 6 months

Have you thought about upgrading

I had my first 20 years ago with old internal device so no

upgrade work with it.

I upgraded in December and Medicare took care of it

Internal portion is called receiver stimulator

External doesn't need changes. There is a life limit

Some kids implanted want to upgrade

Things to think about for cost issues

We are really trying to do clinical trials

We are creating a database if you would like to

participate

If you asked about 60 year old women and how they do, I

would say pretty well but I don't have data

If you would sign a consent so we can have data

We can combine with other centers. We will have 1000's of patients and gives us better information

Diabetics tend to lose hearing, have dementia more

So maybe 60 year olds do well except for diabetics

Do you face any stigmas or negative reactions

Not due to implant no, but prior to, yes

So the hearing loss itself

Before I had mine, in the process of losing hearing, I denied it, I think we all do.

We deny we don't hear what is going on

Before my hearing aids I denied I needed them

I didn't have a huge support group

Looking back, I know I should have gotten hearing aids sooner and looked in Cochlear sooner

When my daughter didn't want me to babysit because I could not hear, I said no.

It is denial

I met a lady a few years ago, already told she is a bilateral person but has fears about the process

Being able to hear I think scares her

You have to reach the point where you step up and think about what gives you the best quality of life

If it was one of your children you would do whatever you had to do to give them best quality of life

I had my implant about 30 years

30 years ago a lot of anti-people in the deaf community

I had to keep my implant quiet



They were very anti implant

A few years after became part of implant club

We have come a long way baby

More and more deaf people getting the implant

When they see how it changes our lives there is no question about it

Cochlear implant is here to stay

For those that have unilateral and not gone bilateral why?

What is the difference

Unilateral is what we have done for a long time

We realize some have single-side implant and other side have hearing aid

I like that

Studies show combining improves outcomes and stimulate nerves

For the future implant

I would say one out of 3 only get the second implant

Why only one out of three

Costs

Some companies cover but not all

Candidate if I am, I said no. I was scared. I was not sure.

Cochlear implant and hearing aid on this side

Sometimes people do so well with one they don't believe

2 people in the group, sometimes exposure

The 2 last areas

Educating people

We talked about the golf outing

My vision is to fund at least one patient per year that has no means to get implants

I appreciate you letting me ask you questions

It helps me

I need to hear what patients have to say

I am blessed to be a part of this world

How better to educate doctors

The goal is to get patient input and get the community involved

Facebook? Maybe the social media route

We have maybe raised about 9 thousand

I have a friend in Dallas they have a foundation they have a ball every year and they funded 6 implants

I would love to see that.

Thank you all for allowing me to be here

I have a question for you

How many do you do

A little more than one a week adults about the same with kids

The oldest patient was 92

I hear people say too old

The problem is not the age, they have to be healthy

I am starting to see more elderly people as long as they are healthy

Anything new on the horizon

Always

New components, electrode arrays

We have to make sure it is safe and works well

I just want to say, I had vertigo for 6 months, after the surgery never came back

Also diabetic

Thank you all

It is an honor to have him

We are going to split up

Next month we will be downstairs

We will have a speaker about cognition and the implants on the 14th of May

What we will do now a split up into groups

We have signs now

If you turn around and look and this is mine

Go to one of the places you would like to talk to someone about the topic

If there is a topic not there come see me

WE ARE LOOKING FOR A MISSING A BROWN PURSE  
AND ALSO A PAIR OF BROWN SUNGLASSES