

Rough Edited Copy

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>>SPEAKER: Hey friends, we are going to get started.
I want to welcome everybody to our June meeting. Thank you for coming with the heat and humidity. It will be worse when we leave.
Good to see everyone. I will ask you a few questions and we can find out who is here.
How many of you are considering a cochlear implant but you don't have one yet?

>>: We don't have one but our scheduled.

>>SPEAKER: How many are scheduled to proceed to have a cochlear implant?

Awesome.

How many here to support someone considering or may get a cochlear implant or has one?

A lot of support people here. Good.

How many already have a cochlear implant and love it?

How many of you have a cochlear implant and you are not so sure yet?

We are going to have some discussion about cochlear implants after we have a speaker. So we will have about an hour maybe a little longer depending on the needs that we will talk to people individually or in small groups about the process of implantation. Or the process of after you are implanted, rehabilitation.

We have plenty of time to do that after our speaker is finished.

Okay.

Couple announcements I want to make:

One is we will have a meeting here next month and Becky Osborne is going to speak, she will tell her story. Raise your hand.

That will be on July 9th. That will be here.

Then in August, we will have a picnic at Brian's house in Delhi. If you don't know where that is, it is on the western side of town. Other side of the world from where I live.

Not hard to get to his house at all but it is a hike if you are not on the west side of town. I am an eastsider. You know about that.

We will send more information about the picnic in an e-mail.

The other thing I want to talk about is upcoming golf outing.

The University of Cincinnati audiology department implant research department is having a fundraiser golf outing in Crittenden Kentucky September 9th.

You can get a team of people together to golf and have a good time and they provide lunch and cart fees. It is 75 a person or \$300 a team. It is a fundraiser to help people that don't have implants and insurance doesn't cover the implantation to get implants. That is part of it. That is what this information is about.

You can pick up one of those there.

Also we have all kinds of brochures and stuff right over here that you can feel free to take -- take that information. It may help you to take that and read on it. Also there is information where you can fill out a form that maybe you didn't see information there and want more information. You can get on the list. So we can send you all kinds of goodies if you want.

So, that is the other thing that is going on.

Any other announcements or things we need people to know before we start?

You all good? You are looking good.

Alright. I would like to introduce to you Roxanne, she will be our speaker and just keep smiling at her because she nervous. She is going to tell her story.

You will do fine.

>>SPEAKER: Thank you.

I sent in my story, I think Brian is making a book or some kind of book for cochlear recipients to tell their story they can handout to Dr. Samy's patients considering to get the implant.

I sent in my story and he said this is a neat story. It is different than a lot of cochlear recipient stories, would you talk at the meeting? I said no. I won't talk at the meeting. I don't do that -- so, but they can read my story.

He said well, I would really like you to talk about it. So here I am.

The reason my story is different is because I have single sided deafness.

That means one ear is deaf and other ear is natural normal hearing without a hearing aid or nothing like that.

I don't know if anyone else has single sided deafness. Anyone here that just has hearing loss in one ear?

The reason I have hearing loss in this ear is because I suffered from sudden sensory nerve hearing loss. I don't know if anyone is familiar with that or has that due to that sudden hearing loss. Anyone have that?

I am not a doctor or clinician, but basically sudden sensory neuro hearing loss is what it sounds like. It is sudden. All the sudden.

Not conductive hearing loss due to loud noises. It is not progressive like over time you lose it. You just wake up and can't hear.

17 years ago I was 30, I went to bed, perfect -- actually I little better than perfect I like to say, I woke up the next morning and couldn't hear.

Things sounded a little off. I went to work and phone rang and I picked it up, hello. Hello. Hang up.

Go to work, the phone rings again, hello. No one there. Phone rings, hello. And I hear hello (far away sounding)

I switch ears and they say I keep calling is something wrong with your phone? No, something is wrong with my ear.

I tried to get in a doctor. I saw family doctor and he said not a big deal, it just sounds like you are under water or been in an airplane. I am like no, it sounds like I am deaf. He didn't do a hearing test. He said it will be fine your ear will pop. I said is there fluid? No. No fluid, no infection, nothing in the ear but you will be fine.

So, I go back to work, I worked for a doctor, a surgeon who was out of town.

She came back in town and I told her and she was like, oh no, this is not good.

She sent me to an ear nose and throat doctor that day. That doctor did a hearing test and he said I have bad news, you are completely deaf in that ear.

I said not, "news to me", I have been saying it for a while.

He said it is sudden sensory hearing loss, it affects the nerve or the tiny hair cells in the cochlea. We don't know what causes it. Who is going to get it.

But, you have it.

We like to start high doses of steroids immediately. Sometimes you can regain some or all of your hearing.

He said it would be like having lightning strike twice.

I think I need to start playing the lotto because it not only struck me twice, it struck me about six more times in my good ear.

I have suffered in the 17 years since I lost my hearing here, six more times I lost hearing in this ear.

I recognize in immediately. I start high dose of steroids for a short time. A week usually.

I have been lucky it brought my hearing back.

I go on about my business and wait for it to strike again.

This is been going on for a while. Last year February of 2015 I had a complete hysterectomy. Everything was fine but I had no hormone levels so I was experiencing the hot flashes and all of that.

Two weeks after hysterectomy I go to bed and wake up the next morning and can't hear.

I immediately start my steroids like I always do.

Once again I regain my hearing and then I discontinue steroids. But this time I start to lose my hearing again.

This is when I go to see Dr. Samy. I saw him previously five years before. I just usually follow my ENT and I know my condition and how to treat it. I see Dr. Samy and he says we need to try more. He gives me higher doses of steroids for a longer period of time.

I get something very pleasant -- it is called intra tympanic ear injection. He takes a needle and shoots steroids into your eardrum, inner ear to help settle inflammation.

I had that done and fortunately that injection with the oral steroids brought my hearing back and had me stabilized.

At this time I am thinking, things are not really going the way I hoped.

Dr. Samy said things are not really going the way we hoped for you. I cannot tell you that you are not going to lose your hearing, I don't know when it is going to happen. If it is going to happen. We know from your history when it does it is probably going to be like that.

I once again say what about a cochlear implant. With the hearing loss I have, the nerve damage you cannot use a hearing aid. It doesn't help. Hearing aids are not an option for me.

When it first happened the doctor said learn to live with it, you are lucky you can still hear out of one ear. I felt lucky. I had little kids. My husband worked and traveled and I worked. I didn't have time to worry about it. I had to get on with life. I felt I was normal, I felt, I heard just like everyone else with two ears.

Now I am getting scared but improbable going to be deaf. I have no form of communication, I grew up in hearing world and don't know sign language. My very supportive family and friends, when I say to the doctor, maybe I should learn sign language. My husband's response is who are you going to talk to? I am like okay, that's a point.

>>: I was joking.

>>SPEAKER: He was joking.

At this point Dr. Samy meets with me and says I know five years ago when we talked, I told you you were not a candidate for cochlear implant. At that time he said you have to be deaf in both ears and then you can get a cochlear implant and I think you would be a candidate when and if that time comes.

When you lose hearing in both ears I think you would be a good candidate. I am like okay, but everything I have heard it takes time to learn to use a cochlear implant. What will I do in the down time? He said we have to wait and see what happens.

But this past February when I started having more trouble and not responding as well as in the past. He said things have changed. We now

Can do cochlear implants for single-sided deaf patients. The problem is it is not FDA approved here in the US.

Because of that insurance companies don't pay for it. Don't have to pay for it because it is not approved.

Now, we know they have been doing this overseas, it is popular in Europe, Australia, here though it has just been a few people that have been able to do it. I think you would be the perfect person to have one. I said I am on board, let's do this.

I want to get trained, I want to have this useful so when I wake up one morning I put it on my ear and can go on about my business.

Dr. Samy's team started working with my insurance company and based on my history and the real possibility that I would be deaf one day, they actually approved my surgery. That was my first miracle.

The problem -- it wasn't a problem but Dr. Samy said, I don't know how this is going to work. I only have a few patients, you would be maybe my 4th or 5th patient I tried it on. A couple don't like it. I am going to tell you, they don't like it. The others say take it or leave it or kind of like it but it is not what they expected.

I am like, okay. He said they are a lot of work. You have to practice, you have to train. You have to make that commitment or it will not work.

He said the other issue for you, different from people that have just cochlear implant. They don't sound like natural hearing. People can tell you they're not like natural God given hearing.

You will get two inputs to your brain. Natural hearing and electronic hearing. Your brain will have to learn to use the cochlear implant but to bring the two types together and integrate them into one useful sound for you.

He said I can't tell you how that is going to work. I said I am all in, let's do this.

In August I have my surgery. It goes flawlessly and everything is great and goes as planned. One thing I have and some people do, dizziness.

I had to delay activation a couple weeks. One thing I want say, not to scare anyone. I got to speak to one patient of Dr. Samy's before my surgery.

If you have not had surgery yet -- there are a lot of support groups on line.

Many Facebook groups you can join and have a community where you can ask questions and learn and get tips and talk to other people that are experiencing what you have experienced.

There were a lot of groups but no one on those sides that had natural hearing in one ear and implant in the other.

So, I was kind of one of the first. But I did get to speak to one patient and she had hers about a year and a half or almost two years. She said I like it now. I

didn't like it when I first got it. She said I will be honest, I don't practice. I put it on and I go about my day. So it took months, months, and months. She said I am probably not where I should be. I don't practice.

She said I want you to understand it is not that good when you are compare it to your other ear. She said I know you saw the videos of people getting it turned on and crying. They turn it on and hear sounds, tears of joy. She said I cried too because I couldn't believe how bad it sounded.

I thought oh my gosh, what have I done.

She said as time goes on you get used to it. You learn to hear and over time it becomes more natural and normal. But you have to be patient. Do not go there and have that thing turned on and think oh my God, what have I done? That is not what it is going to sound like from on out. It will get better every day and you will practice and it will get better for you.

She said don't let that scare you. She said I am not afraid, I am doing this.

They turned it on and low and be hold there was sound. I call it noise. I couldn't distinguish sounds and voices from a car running, from a dog barking, from a book closing. I heard and noise and sound everywhere but it was just like a jumble.

So I went home and started practicing right away.

My audiologist, Theresa said don't practice too much. I am an over achiever, I am practicing. So I started practicing.

Another issue I had, which I think is pretty rare -- when they activated the implant, when I would get sound at the beginning, I would get sound and standing or walking it would throw off my balance.

The only real remedy was to keep getting sound and keep walking. I wasn't very good at it. My neighbors thought I was on a two-week bender. I would walk every day and staggering. I would take daughter, son, husband or friend. I would be staggering around every day. Every day my staggering got less. With less than a week I could walk alone and keep getting sound.

The brain had to learn to take this sound it didn't have for 17 years. Do two things at once. Get the sound and balance.

That is not common but it happened to me. Anything rare I can figure out how to make it happen.

From that point on I did rehab and angel sound.

The difference in practice for me and most people is I can hear. I have to isolate my hearing ear so I only hear when I practice with my cochlear implant.

That is not easy to do. I can put in earplugs but I can still get sounds.

My secret weapons are the phone clip and the mini mic. These are to help people with cochlear implants hear better in different situations.

If someone had the mini mic here I could clip it on and it would pick up my voice through the microphone and send it directly to the implant.

Does anyone use these items?

The mini mic works that way. I can put it on the table and turn it on and it helps me to pick up more voices at the table. Sends it directly to my processor.

The phone clip is used to help people when they are using the phone. Like I

phone or whatever.

I use mine in a different capacity. Basically this is Bluetooth ready. Anything with blue tooth you connect this to and it will send sound to your processor. People use this to hear better and I use these to do my practice with. I use audio books, angel sound. I hook this up to the computer and turn it on and plug it into the headphone jack in the computer and it streams the sound to my implant and no one else in the room can hear it. I can sit in a room of people and do my audio books. I use them religiously. I am an avid reader and love reading. This is my excuse because I don't have time to read anymore. I have to go do my therapy. I plug in my book and I listen to it. I also use this and plug it in -- a trick I found is I plug into the TV. When I am cooking or doing dishes I plug this in and listen to it. No one else can hear the TV. I am not bothering anyone. I started with newscast. They were the easiest for me, plus I could combine lip reading because newscasters are looking at you. As time went on I was able to get more and more. Now I practice with talk shows. It is more sound so it is more challenging. I keep challenging myself that way.

>>: Can you use that without -- can I plug into back of TV in my room?

>>SPEAKER: If it was headphone jack, yes.

>>: I have one for the main room TV thing but I can plug that into any television as long as I use the cord in the back of the TV.

>>: That is a regular plug like any other headphones. You can go to Amazon and get a blue tooth transmitter for 10 or \$15.

You would have a cord like this to that device and you plug this into whatever jack and it will send it out blue tooth. I have about five of them. Cars, office. I am a geek if anyone wants any. I am her husband by the way. If anyone wants to talk about devices I have you covered.

>>SPEAKER: The rest of you, I have to be more creative so I only get sound to this.

You will be able to practice much easier because any sound -- you just want to take in all the sound.

When I practice I take these and the rest of the day I put this on my head and go about my business.

During the day I am wearing it and my brain is integrating the two different sounds. When I practice I am only practicing to make my implant work for me so I can understand speech if and when I have to use. This is my only form of hearing, I want to be ready.

Basically two different types of practicing.

>>: Are you actually using the cochlear implant during the day.

>>SPEAKER: I wear it all day every day. They are integrating.

It has been about nine and a half months since I was activated.

The benefits to me because I do have hearing and I have for 17 years. I function very well. People say, Dr. Samy is one of them that says what do you think? How is it working? Would you do it again?

With this one of my most favorite feature is I have directional hearing again.

So when I am walking, when I need to cross the street, I could hear a car coming before but I didn't nowhere. I would be this all the time.

When I would walk, people could ride a bike, a dog, a person, they would have to be right up on me before I would know they were there and then it was like where did you come from.

With this I can hear joggers, bikers, behind me, I can tell where a car is coming from.

About four days after activation, I couldn't hear individual sounds and couldn't understand speech but we were at elevators and the elevator bell went off saying the elevator is here. I walked over and got own. I didn't think anything about it and my husband went -- do you know what you just did? I said yeah, I got on the elevator. He was like, you don't know what you just did? I was like I got on the elevator. He said yes, you did but when the bell went ding you didn't do this. (Laughter) you went straight to the door.

Everyone says you will have the cochlear moments and that was my first "oh my gosh".

The other really nice thing is I can function better in loud environments.

Restaurants, parties, weddings. I would avoid all of that. I would be sitting there and everything going on and I would be going (Indicating)

My family and friends the waitress would come up and say everything okay, everything okay? They would be on my deaf side and I was be like -- then they would be like is everything okay. They would say it's okay, she can't hear right.

>>: We are not really that mean.

>>SPEAKER: Humor makes things easier.

Another really funny part -- not funny, but our best friends, husband and wife couple. He has single sided deafness in his left ear. He lost it at five from the mumps. I have it on this side. When we go to restaurants it was like musical chairs. Everyone would sit and stand and say this won't work. Switch seats and then I need to sit here. The staff would be like is everything okay and we were like it is fine we are just deaf.

It is really nice in loud environments and can sit where I need. I don't have to come early anymore to make sure I am in the front row. I don't have to sit in the front row at church anymore.

I don't have to extend a lot of energy lip reading. I would talk to people and make them uncomfortable. Most people didn't know I was deaf in one ear. I would talk to people and stand close and staring intently at their face and they would be like okay.

I would say by the way, I am deaf, I am not trying to kiss you. (Laughter)

That is pretty much where I am. It has been ten months. I am not going to lie. When I was activated it was overwhelming. Especially it would over power my natural ear. By the end of the day I would be at my wit's end. 8:30 I would take it off. They would say wear it wear it wear it. So I wore it and did my therapy.

If someone asked me about this with single sided deafness. I would say if you are willing to commit to it. With single sided deafness, I can take this off and

still hear. It is not always convenient to have one of these. If you want to swim, if I am outside working. Sweating. Many times I am like I am just going to take this off, I don't need it. You can't do that.

If you are going to make the commitment to wear it as single-sided deafness it is worth it. If you practice it is worth it.

A lot of e equipment.

When you travel there is a lot of -- I have my travel case.

It is not super convenient -- for me it is fantastic. Not only does it enhance my daily life but it is that -- it is the insurance, it is my insurance and my reassurance that when and if I lose my hearing I have something in place.

That is really all I have. I have different methods of -- that I can talk about. I use all kinds of different training methods to practice with, if anyone wants to talk to me about that I can do that.

I will name a few.

Audio books. I started with that and had to read along with the book while listening.

By the fifth book I didn't need to read along anymore.

I still do daily audio books. Maybe ten minutes, hour, sometimes more.

Another interesting thing I found is Ted talks. There are thousands of them.

Different speakers talk about different topics. You can find them on You Tube.

On the phone. I get to hear different speakers, accents, topics, keeps me interested and exposes me to a variety of different voice types and male and female.

I mentioned the TV, newscast, talk shows. Things like that.

For music I use Pandora. Amazon prime has music and lyrics you can follow along. Pandora has menus where you can read the lyrics. Sound hound is another one.

Cochlear has something called phone with confidence. She change that every day. You call the 800 number. There is no pressure to talk on the phone with a live person. You can listen to daily words that change every day.

They have a short passage and a long passage. They have different speakers you dial up and say I want to hear the long passage. They have different speakers everyday so you get used to different types of voices on the phone.

On the website you can pull up the script. If you can't understand on the phone, which I could not. They have the script for that day and you can read along while you are listening through the phone.

That is when you would use the phone clip.

>>: Only through the phone or can you use the computer?

>>SPEAKER: The phone clip -- it is an 800 number. It is with your phone. I guess -- you can call from any phone but you need the phone for that. But you find the script on line at their website.

Another one I used in the beginning, it was through Med al. That is another company. They have continents and oceans and it would tell you to click on this and this and Africa, South America. You click and sometimes you get it right and sometimes you don't because you are not sure what they are saying. You just keep doing that until you get a handle on it.

Anyone has further questions about that stuff or questions for me I would be happy to answer before we break out into individual groups.

>>: You said it took you ten months to get the full effect of it?

>>SPEAKER: No, I am ten months in. It still gets better. I still see improvement. I still have a lot of work to do.

But in terms of using it just -- when I say that I mean as only the cochlear implant itself. Not using my other ear. Just using it as cochlear implant, I have a lot of work to do. But I also am only training my ear while I am practicing. Where you all will have the cochlear implant and using it all day long with just the cochlear implant. For some people it is faster. It is a little slower for me because I am really only working the processor of the implant when I am practicing. The rest of the time my brain is learning to use both forms of hearing at the same time.

The both forms at the same time, that is pretty good I think. In actuality, I think the implant sounds just about normal when I am hearing in conjunction with my other ear. It is like wow, this sounds normal. I am getting all of this and understand all the words.

Then I will just go -- yeah, maybe not.

It is an adjustment and really great with this ear but just using it alone I still practice.

I know Brian, I don't know how long he has his but he still practices every day. The more you practice the better it will be.

>>: If you are deaf in one ear and limited in one ear, it better to do one ear?

>>SPEAKER: You would work with your audiologist but from the groups I saw -- if you have a hearing aid in the other ear they will advise you to go without that hearing aid as much as possible to make this stronger. Physical and when I lose hearing in this I would see a rapid improvement in this over what I have now. It is just, your brain is going to pick your dominant ear. Everyone has a dominant ear. This is mine. I can't change that. So I have to work with what I have.

If I lose hearing in this, this will be my dominant ear until I get my second one. There will be a second one. I like being bilateral. I didn't think I needed it but now I like it and I don't want to lose it. If I lose this, I am getting another one.

>>: I am somewhat confused. I am a new recipient, when you say practice, do you mean imputing information into the --

>>SPEAKER: Sound.

>>: Okay, that answered my question. I am confused practice what -- but that is that is what I took it as. Speaking with the doctor and everyone else, they use that term a lot and I wanted to clarify that.

>>: I have to add to that because this is another funny part of that. She has to the point with the devices when practicing. I have an office separate from the house in the woods. I am going back and forth and I will be behind her talking already.

(Sigh) what?

When she practicing, she is sitting nice and silent and you think she is chilling and she is actually working this and enjoying it at the same time.

Another thing to add to what she has been saying that hasn't come through in her talk but she has not appreciated what we have seen develop in her. Over time, you can see that the things are getting better. It is amazing what the brain can do.

You start putting this information in there and it starts doing thing.

Theresa commented but we went to the meeting, she was talking about working hard and practicing. She has worked hard at this. She will have spells when there is no time but then she gets to it. It makes such a difference over time. She made comments that it is so much better than she dreamed it would be with the convergence of both ears and how it has turned the processor into working for her.

The perception is a good ear. You get the -- a lot of you -- she is blessed to have the good ear.

The ability to become a good ear versus the electronic Donald Duck sound.

>>: When you were healing did you get an itch in your ear?

>>SPEAKER: By the incision, yes. That is normal hearing. If you have a rash or discharge that is not good but itching is part of the normal hearing loss. I can tell you that because I work for a surgeon so I have given that talk many times. I would lightly press, you don't want to do that.

>>: I know a lot of times -- sometimes I use alcohol to stop the inches. Can't use finger nail --

>>SPEAKER: Yeah, sometimes just like that.

>>SPEAKER: What we will do is break into groups. Before we do that I want to recognize Roxanne for A the beautiful job she did. We will call on her more often to share that story.

That is great.

Everyone's story is different. Just because you hear that story don't think your story will be the same, it is not. There may be similarities but it will not be the same story. Everyone is starting at a different place and the surgeries maybe different and your rehabilitation will most likely be unique for you.

Don't get discouraged if you are newly implanted person and it doesn't happen the way she said. Work closely with your audiologist and doctor and be patient. Good luck with that, I was not that person.

>>: That is why we are called patients.

>>SPEAKER: What we will do now is divide into groups so you can ask questions that are pertinent for you.

Back in this corner we have Laurel who is an audiologist and someone newly implanted and just starting the rehabilitation process or have questions about things directly after surgery. Go back there and maybe Theresa can maybe go back there too. I appreciate that.

Then we have -- is an implant right for me: Janice is back there if you want to go back and talk to her she can maybe help you through -- think through what you need to think about.

If you are scheduled for surgery: Mary Jo will talk to you about what that process looks like. Or any other questions.

If you are long term recipient and have questions, Lou Ann will meet with you.
If you have a hybrid implant or considering a hybrid implant that is me.

>>: What is a hybrid?

>>SPEAKER: It is for someone who has lost some of their hearing but not all of it and you get a combination cochlear implant and hearing aid.

If you are a candidate for that, they will tell you. You have to qualify for that. Not everyone here is. There are a few of us with hybrids.

>>: He has a little bit of hearing and this year dropped dramatically.

>>SPEAKER: They will tell you our doctor or audiologist will tell you if you qualify.

If they have not told you and you are scheduled for surgery, probably not.

Any general questions that anyone has that we could answer before we split up?

I know some of you are schedule really soon, right Robin?

>>: You guys were talking about the phone

I am getting a buzz here and didn't hear that.

>>: The clip at the phone can you use it at work?

>>SPEAKER: Sure. Absolutely. I use my phone clip all the time. Right there. Yeah. Work, whatever.

Those are accommodations that your employer should allow you to use. It is part of your disability and required by law they accommodate you with your disability. They need to let you use that. If it is a problem you need to go to the American with disabilities act. Say this is a problem I need this.

That is an important question.

>>: I was wondering, show of hands -- does everyone have fluctuations in their hearing. I have implant and I go a couple weeks and it goes down and gets better. Fluctuations.

>>SPEAKER: You will have to ask the audiologist about that.

>>: Fluctuations is normal depending on the reason for hearing loss. That would be something to ask your physician or audiologist. Not everyone has fluctuations but some people do.

>>SPEAKER: I will get more water out so take water if you would like.

Mary Jo, you will go in the other room.

People scheduled for surgery want to go with her.

>>: We are waiting to hear about insurance before we schedule.

>>: If we have questions about technology, attachments, would Roxanne's husband --

>>SPEAKER: Roxanne's and Chris will talk about technology.

Newly implanted back there.