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BUFFALO IMPLANT GROUP
Meeting Transcript

Daemen College
Williamsville, New York
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Closed Captioning Provided by:

Chrisann Hyland

Linda Cancilla

Chrisann Hyland
Western New York Court Reporting Services
(716) 830-0950
buffalocourtreporters.com

1 JOE KOLIS: Welcome everybody. This was
2 the room that was available. We hope for
3 future meetings to be back in our room again
4 but we are at the mercy of Daemen's
5 scheduling. So we really appreciate them
6 giving us the room so here we are.

7 I want to introduce myself. I am Joe
8 Kolis, I am the president of BIG.

9 We have Kathy Maroney with the red
10 sweater back there; Lisa Hill Nowicki is our
11 secretary; Sam Spritzer up here is our
12 treasurer. Craig and Jackie, it is their
13 49th wedding anniversary so they are out
14 celebrating. Gail Cronin is here and Shirley
15 is not here yet.

16 I want to go over a few items of
17 business before we get started with our
18 speaker. At this meeting traditionally we
19 held nominations for officers. I don't
20 normally put anybody on the spot but I would
21 like you to consider running for an officer
22 position. If you are interested, please go
23 ahead and give me a call, stop one of us on
24 the side and just let us know if you are
25 interested in any of the positions, they are

1 all open. And here is Shirley as we speak.

2 We did get ready for the winter coming
3 up. We are in the process of getting the
4 weather cancellation information out to the
5 TV and radio stations. Lisa Hill Nowicki is
6 in charge of that. If you want to give us a
7 list of the television stations and radio
8 stations that you contacted.

9 LISA HILL NOWICKI: It takes a couple
10 weeks for them to enter it into their data
11 processing system. I requested to be on the
12 weather scrolls for Channel 2, Channel 4 and
13 Channel 7 as well as for WBEN radio.

14 Have I missed any station that somebody
15 listens to I can always add it to another
16 station. But those are the main stations
17 that I sent it out to. But if we do cancel
18 our next meeting due to weather, hopefully it
19 will be on the scrolls for all three
20 channels: Channel 2, Channel 4 and Channel 7
21 as well as WBEN. Thank you.

22 JOE KOLIS: If you recall last winter we
23 had a late afternoon snowstorm come in and
24 there was a lot of confusion whether we would
25 cancel or not and some people did not get the

1 message so we will try our best to get the
2 information out there as soon as we can. If
3 there is any question or doubt in your mind
4 about bad weather, please turn on the TV and
5 check your e-mail, Craig will send out an
6 e-mail as soon as we make a decision. But
7 around here it is tough to know at 4 o'clock
8 exactly if the weather is going to turn worse
9 or get better. Last time we erred on the
10 side of caution to make sure we do not have
11 people on the road in a dangerous situation.
12 Hopefully we will not have bad weather for
13 our March meeting, but if we do, tune in to
14 TV and radio.

15 We want to thank Linda and Chrisann for
16 our CART services. They have been great on
17 short notice. We had some e-mail mix ups and
18 they are here on short notice. And we really
19 do appreciate the service you guys perform.

20 I work for National Fuel and as part of
21 the consumer affairs group we offer HEAP. It
22 is the energy assistance program. The income
23 guidelines for it have really gone up quite a
24 bit. I have applications here. I did notice
25 they didn't put the card for income levels

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Western New York Court Reporting Services
(716) 830-0950
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1 but if, I believe for a household of two I
2 think the monthly income is about \$2500.00 so
3 it has actually gone up quite a bit and I
4 encourage you if you know someone who can
5 benefit from the program come up here and
6 grab an application. I don't work in that
7 department so I don't have all the
8 information but I wanted to bring the
9 applications here because the money and the
10 funds for the program is limited. And I
11 wanted to let everybody know that if any of
12 us or anybody in the group or anybody that
13 you know, a friend or relative, someone that
14 could qualify, the income levels increased
15 quite a bit last year. So feel free to grab
16 an application. I don't have all the answers
17 about the program but there is a phone number
18 to call to get it and feel free to take one.
19 I can answer some basic questions but that's
20 about it.

21 I want to let you know our pizza will be
22 here at 7:30 after the meeting. Please hang
23 out with us and I will get reacquainted with
24 everybody. With that, I will turn everything
25 over to Tina Childress and she will talk to

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1 us about travelling with hearing loss and
2 cochlear implants. Here's Tina.

3 TINA CHILDRESS: Thank you so much, Joe.
4 So thank you very, very much for coming out
5 here today.

6 Speaking of travel, when Joe approached
7 me about coming to Buffalo and we were trying
8 to figure out a time and we settled on
9 November 30th, I thought, I am travelling to
10 Buffalo, New York at the end of November,
11 what am I thinking! So I made sure when I
12 made my plane reservations to get the trip
13 insurance which is an extra twenty dollars so
14 that if something were happen to my flight I
15 knew I would have it taken care of. I am
16 very thankful that everything worked out and
17 my flights were on time and it was great.

18 A little bit about me. I live in
19 Champaign, Illinois, that's about two and a
20 half hours south of the "State of Chicago" as
21 we call to call it.

22 (laughter)

23 I grew up near the Chicago area and came
24 to Champaign for college and it is like a
25 black hole and I never left.

1 I am an audiologist, for those of you
2 that don't know me. I am an educational
3 audiologist which means I work in the schools
4 and I work for children that have known
5 hearing loss and supply them with assistive
6 technology, and I go to meetings and things
7 of that nature.

8 I also do some consulting for
9 residential schools, so the school for the
10 deaf. And they have really great vision and
11 they hired me to be their cochlear implant
12 specialist. So they know more and more kids
13 are getting cochlear implants and we are even
14 seeing them in their residential schools.
15 They wanted to make sure that their needs are
16 taken care of. I do some consulting and I
17 travel around the state doing technical
18 assistance and things like that.

19 Before I, before this job, I will
20 backup. This is the position that I had when
21 I graduated from school. And then I took a
22 three-year break and I actually worked for
23 Advanced Bionics, one of the cochlear implant
24 companies. Some of you were here the last
25 time I came out I think I was working for

1 Advanced Bionics so I did that perspective
2 working on the industry side. I am really
3 happy to be here.

4 I do a lot of traveling. I fly a lot, I
5 drive a lot. And I am hoping that some of
6 the information that I have here today will
7 help you in your travels especially during
8 this holiday season.

9 Can you all hear me okay? Am I talking
10 at a good rate? Not too fast or not too
11 slow? Fantastic.

12 These are the topics we will be
13 covering: When you are on an airplane, some
14 hints if you are going to travel by train, by
15 automobile. We will talk about some of the
16 assistive listening devices that might help
17 you hear better in some of these situations.
18 I will talk about what to pack. We will
19 discuss power supplies. So if you have a
20 cochlear implant and you need to charge your
21 batteries we will discuss some of the issues
22 related to that.

23 And then lodging, I think I talked to
24 Dorothy about what happens when I go to a
25 hotel and I don't want to lug my personal

1 alarm clock with me. I will tell you about
2 some of the things that are in place for
3 people with hearing loss already under the
4 law.

5 And then also, this is something that
6 unfortunately not a lot of people know about,
7 what to do if you are in an emergency. You
8 know, what happens if you are in a car
9 accident. I was in an accident where I was
10 actually rear-ended and the car hit me and my
11 implants flew out and so then I could not
12 hear. First of all, I was disoriented
13 because I just got hit and then I was
14 disoriented because I could not hear and it
15 took awhile to find my implants because they
16 stuck underneath the seats. The head piece
17 magnet. We will talk about some of those
18 issues, too.

19 These are some common questions people
20 will ask. Well, I will travel by airplane,
21 you know that big thing when you check your
22 luggage and they take it away and they put it
23 through this big machine, okay. I would not
24 recommend putting any of your cochlear
25 implant equipment in your luggage that goes,

1 that needs to be checked. If you are going
2 to travel and you are carrying extra head
3 pieces or coils or an extra processor or
4 extra batteries, you want to carry that with
5 you in your carry-on bag. There are
6 instances where equipment has gone through
7 this piece of, this scanner and there have
8 been reports it can wipe out your map on your
9 cochlear implant so I would not recommend
10 that.

11 AUDIENCE MEMBER: Before I go through
12 that machine I showed the ID.

13 TINA CHILDRESS: Yes.

14 AUDIENCE MEMBER: But you should have
15 seen their face. They did not understand,
16 they said, what is this for? What is this
17 for? I said, I have cochlear implants and
18 they said, what is that? So how can we solve
19 the problem? They said, go ahead, nothing
20 will happen, and I feel --

21 TINA CHILDRESS: I will discuss that in
22 a little bit. That is a different piece of
23 equipment. This is just for luggage. And I
24 will talk about what happens when you go
25 through the metal detector, okay. I am just

1 trying to go step by step.

2 First, you check in at the desk and you
3 say, here's my luggage, and you give it to
4 them and they make sure it is under fifty
5 pounds and then it gets packed away. That is
6 the luggage you do not want any of your
7 equipment in.

8 Second, they check your ID and they
9 check your ticket. Then you have to take off
10 your shoes and take out your laptop and that
11 is what this is about.

12 So let's say you have your cochlear
13 implant equipment. If you are going to take
14 it off, and you "don't" have to take it off.
15 You don't have to. But if for some reason
16 you take it off or maybe you have a spare
17 processor, do not put it on that rubber mat,
18 okay. You want to make sure to leave it in a
19 bag, like a carry-on bag. Or at the very
20 least, put it in one of the dishes, they give
21 you those little dishes or bins that you can
22 put your keys and your cellphone in. Do not
23 put it directly on the mat because that is
24 rubber and it can generate static electricity
25 and static electricity can also wipe out your

1 map.

2 There has been discussion, there was an
3 instance where a lithium ion battery, and
4 these are the kind of batteries that you
5 might find in your laptop computer. They are
6 the kind of batteries that we all use for our
7 rechargeable batteries, it is always
8 recommended that those batteries stay with
9 you also.

10 There is something that happened where
11 someone had a bunch of lithium ion batteries
12 for computers and they put it in the luggage
13 that went underneath the airplane and it
14 caught fire. The lithium ion batteries catch
15 fire very quickly so now they are saying
16 lithium ion batteries need to be in the cabin
17 so that if something happens it is easy to
18 put out the fire quick.

19 Someone might ask you, the TSA people
20 might ask you what kind of battery is that
21 and so you can say, yes, this is a lithium
22 ion battery for my implant, and that might
23 help, okay. So do not put anything on the
24 rubber mat. Carry all of your equipment with
25 you.

1 The walk-through metal detector. You do
2 not have to take off your implant or implants
3 or your hearing aid. It used to be if you
4 had the old body processor, there is a lot
5 more metal on the body processor, and that
6 might set off the alarm. If you have an
7 ear-level processor, you do not have to take
8 them off. The body one, you would have to
9 take off because it will set off the alarm so
10 you can ask to be wanded or you can take it
11 off and put it in one of those trays.

12 On the TSA side, Transportation Security
13 Administration, they actually recommend that
14 you leave your hearing aid or your cochlear
15 implant on so that you can communicate with
16 the TSA people as you go through. So when
17 you showed them that card and they had no
18 idea what that was, that's unfortunate. They
19 are supposed to know about devices like that.
20 You might say it is like a very powerful
21 surgically implanted hearing aid. That might
22 be the only way they understand what that
23 means. It might be an opportunity to educate
24 them about cochlear implants. But your
25 cochlear implant company also should have

1 given you a travel card that discusses that
2 it is okay to go through the metal detector.

3 AUDIENCE MEMBER: My daughter works for
4 TSA and they know what a cochlear implant is.
5 She does know.

6 TINA CHILDRESS: So the comment was that
7 her daughter --

8 AUDIENCE MEMBER: It might be somebody
9 that just started and didn't know.

10 TINA CHILDRESS: Her comment was her
11 daughter works for the TSA and they do know
12 so she thinks maybe that person was brand new
13 and didn't know about cochlear implants. Or
14 maybe wasn't paying attention when they were
15 talking about it.

16 (laughter)

17 AUDIENCE MEMBER: Many of the TSA
18 officers, or people, you know, that have
19 limited intelligence as far as people with
20 cochlear implants, they are extremely
21 suspicious of these things and there is
22 malicious intent tearing apart your equipment
23 and I have had problems before. How do you
24 deal with these people when they are really,
25 they do not care if they rip your stuff

1 apart. You know the wires are very fine and
2 fragile. And sometimes they insist to put it
3 through the X-ray so they can burn out your
4 system.

5 TINA CHILDRESS: Well, it is not going
6 to burn it out.

7 AUDIENCE MEMBER: Well, it will kill, it
8 may have a possibility of killing your
9 mapping.

10 TINA CHILDRESS: Only if it is on the
11 rubber mat, but going through that machine it
12 should not do that. I had my equipment go
13 through hundreds of times.

14 AUDIENCE MEMBER: You are talking about
15 the machine --

16 TINA CHILDRESS: This is my, this is my
17 lingo thing where you take off your shoes and
18 put your computer.

19 AUDIENCE MEMBER: That will not hurt
20 anything?

21 AUDIENCE MEMBER: No.

22 TINA CHILDRESS: Yes, Joe.

23 JOE KOLIS: But can you request not to
24 go through any of the machines?

25 TINA CHILDRESS: Yes.

1 JOE KOLIS: We just went with our family
2 to Orlando and I wouldn't let Jillian, we
3 would not put anything through the belt and I
4 wouldn't let her go through the metal
5 detector either. And we went on the side and
6 just requested a wand and a pat down. But
7 they did want to look at the wires, too, but
8 we were just, like, all right, look at it and
9 I was hovering, I was right there.

10 (laughter)

11 AUDIENCE MEMBER: I do that, too. I
12 talk to them before I go through there and
13 tell them I have a cochlear implant and if I
14 take it off I will not be able to hear and
15 they always tell me, keep it in your hand, go
16 through there and hand it to the girl and
17 then she will give it back to me.

18 TINA CHILDRESS: But there is no reason
19 you need to take off your equipment. You can
20 absolutely go through that and it is not
21 going to affect anything. Sometimes people
22 will report they hear a funny noise when they
23 go through. Like that happens to me when I
24 go in and out of the library. I hear a weird
25 noise like a buzzing sound and then I'm okay.

1 AUDIENCE MEMBER: Well, I always when
2 travelling by air, it is just now and then, I
3 immediately tell them when I am taking my
4 shoes off that I need to be checked manually
5 and they are as nice as can be. I even tell
6 them do not use the wand and I tell them I do
7 not need privacy. You can request privacy.
8 And it is no problem and I just prefer that.
9 But I never have any problem.

10 The only time I had a problem, it is
11 funny, in the Niagara County building, and
12 this is like twenty-five miles from here,
13 nobody knew a thing. They didn't know a
14 thing and they were giving me trouble. I
15 just asked for their supervisor and that was
16 that. But I think, I always carry the two
17 cards with me that I am a double cochlear
18 implant and I carry the cards with me. No
19 one has ever asked to see them.

20 TINA CHILDRESS: I think we all had
21 different experiences and it sounds like
22 everyone has a preference and comfort level
23 with what they want to do. I think it is
24 great to know that we have that choice. We
25 have the choice to be patted down or to be

1 wanded or to just go through.

2 I know that one time I was with a
3 gentleman, and his implant, you could see his
4 implant very much and they wanted him to take
5 it off because they thought it was a
6 Bluetooth device.

7 Funny story, I was travelling and I was
8 changing the battery on my implant and the
9 lady saw the blinking light and she said, is
10 that red tooth? I never seen red tooth
11 before.

12 (laughter)

13 And then I said, oh, I can show you
14 green tooth when I put it on my head and it
15 blinks and I talk. When I change my battery
16 it is orange tooth.

17 (laughter)

18 They designed the cochlear implant to
19 blend in. This is designed to look like a
20 Bluetooth device.

21 You hear horror stories of, I remember
22 working with a parent and she was chastised
23 by another parent because her son had
24 bilateral implants and he was like, four, and
25 this mom said, why are you putting Bluetooth

1 already on your four-year old? Because she
2 didn't realize they were cochlear implants.

3 AUDIENCE MEMBER: What is a Bluetooth?

4 TINA CHILDRESS: People do not know what
5 they are. And I always take the opportunity
6 to educate them. I say I am deaf. And these
7 are ways that I hear and it is a surgically
8 implanted device so kind of funny stories
9 like that.

10 We talked about the fact you may hear a
11 distorted sound. If you are one of those
12 people that you consistently hear this
13 distorted sound, well then I can understand
14 why you want to take your device off as you
15 go through the scanner.

16 We talked at length about the ID cards.
17 How many people do not have an ID card that
18 they remember getting from their implant
19 company? If you do not, I would contact the
20 customer service department for your cochlear
21 implant company and they will get you one.
22 And if you find that you do have a weird
23 noise, try turning down the volume before you
24 go through the scanner so it is not too loud.

25 And we talked about some of the

1 alternatives. You can get wanded or you can
2 get the pat down.

3 The TSA also on their website has this
4 card that you can bring also. I don't think
5 you need to have four different cards talking
6 about the fact that you have an implant. But
7 if this is something that the TSA people are,
8 like, I don't know what this is. Maybe it
9 will have more credence if it comes from TSA.
10 It is their own card. That is something you
11 might want to investigate.

12 When you travel by plane and you check
13 them in, I know that my airport is extremely
14 small and the TSA guy goes to my church. The
15 lady at the desk uses the same daycare I go
16 to. I am like Norm on Cheers and they are
17 like, hey, Tina, where are you going today.
18 I have at most three people in line ahead of
19 me when I check in at the airport. If you
20 let them know ahead of time that you have a
21 hearing loss and you stay really close to the
22 desk and anytime there is a gate change or
23 something like that, just remind them, please
24 let me know that I cannot hear in this
25 situation and please let me know. Often

1 times they will let you preboard. You can go
2 in ahead of time.

3 The other thing, at least for American
4 Airlines and I think this happens with other
5 airlines, they will actually put on your file
6 that you are deaf. I have gone to airports
7 and let's say I wanted to get upgraded, they
8 say, oh, I notice you are deaf, is there
9 anything I can do for you? And so that is
10 really nice, too.

11 If you have a cellphone or a smart phone
12 where you can get e-mail or texts, these are
13 lifesavers. There have been times I have
14 gone to the airport and I really want to work
15 on something and I actually take off my
16 implants but I always have my phone next to
17 me because if there is a gate change or if it
18 will be delayed, I will get an alert and you
19 can sign up for these alerts when you make a
20 reservation. And when you check-in, there is
21 always a check box that says sign up for
22 alerts.

23 Yes?

24 AUDIENCE MEMBER: You are supposed to
25 take them off when you are flying in an

1 airplane?

2 TINA CHILDRESS: No.

3 AUDIENCE MEMBER: I have been told you
4 are supposed to.

5 TINA CHILDRESS: No, that is not true.

6 AUDIENCE MEMBER: Leave it on?

7 TINA CHILDRESS: When they say turn off
8 all electric devices, they mean cellphones or
9 iPads. Things like that, they will not make
10 someone turn off their insulin pump or take
11 off their hearing aids and the same holds
12 true for cochlear implants. Once again,
13 people see this thing on your head and they
14 think it might be Bluetooth so you never
15 know, you have to tell them this is my
16 hearing device. And then once again you are
17 the one responsible for letting the gate
18 people know you have a hearing loss.

19 I have been to plenty of airports where
20 I had to run to the next gate because I did
21 not hear an announcement and something
22 changed. So when you are on the airplane
23 know that hearing aids and cochlear implants
24 will not affect the navigation system. And
25 that's what I was just talking about.

1 Now when it comes to watching movies or
2 listening to music on the plane, there is
3 still no captioning for the in-flight movies
4 which is a sad thing. I know that people
5 like HLAA and ALDA are trying to fight to get
6 that more accessible for people that have
7 hearing loss.

8 If you are able to use things like
9 headphones or if you have a neckloop I
10 encourage you to use those things on the
11 airplane if it helps you hear music better on
12 the airplane.

13 So if you travel alone, and I often
14 travel alone, I usually will tell the person
15 sitting next to me because I like to sit in
16 the aisle because I go to the bathroom all
17 the time and I hate climbing over people. I
18 always tell the person sitting next to me
19 that I am deaf and that if I fall asleep that
20 if they need to get up and they are talking
21 to me that necessarily will not help and at
22 that point go ahead and tap me on the
23 shoulder, it is totally fine. I actually
24 often take my implants off in the plane
25 because I have had instances where I have

1 fallen asleep with my implants on and I wake
2 up and my implants are not on, because they
3 have fallen off and like my head moved and it
4 has just fallen off. And I don't need to
5 hear all the plane noise anyway so I tend to
6 take my implants off in the plane.

7 It is still important, though, to tell
8 your seat partner and you also want to tell
9 the flight attendant that is usually walking
10 through as you get on the plane, tell the
11 flight attendant that you have hearing loss
12 and if there is any important announcements
13 to be close to me to talk.

14 I have had flight attendants actually
15 write down the next gate on a napkin and just
16 give it to me. You know, as they descend
17 they say if you're going to Tampa you will be
18 in Gate B5 or if you will be in Chicago it's
19 this gate. I had attendants write it down
20 for me and give it to me which is very nice.
21 But it is very important that they know that
22 you may not be able to hear in case of an
23 emergency.

24 I never sit in an exit. If something
25 happened and my implants are off, I am not

1 safe in an exit.

2 One time, so I'm talking about falling
3 asleep on the plane, when my implant falls
4 off, it blinks a red color. And I remember
5 one time my implant fell off and I was asleep
6 and all of the sudden I felt this tap, and
7 over the seat you can tell the lady was,
8 like, this, I don't know if she thought it
9 was going to explode because it was a red
10 blinking light and she was probably just
11 trying to be very gentle with it but I'm
12 telling you this blinking light is awesome,
13 especially when it is dark. I lost it in a
14 movie theater when I put on my coat so I
15 hsome funny stories like that.

16 Are there any questions about travelling
17 on an airplane? I know that is where most of
18 the questions come from, can I do this or can
19 I do that? Are we all clear? Awesome.

20 Let's talk a little bit about the train.
21 Once again as you board the train let them
22 know you have hearing loss. I think Union
23 City in Washington DC and also New York City
24 is crazy. If there is a gate change or
25 something like that and you are not aware,

1 you might miss your train. There is always
2 horror stories of deaf people getting hit by
3 a train. I know there was a story several
4 years ago where a teenager or something like
5 that was crossing the tracks and they got
6 killed so you always want to be very aware of
7 your visual -- of your surroundings.

8 Once again, if you are travelling alone,
9 let the people that are sitting around you
10 know that you cannot hear. When I travel by
11 train from Champaign to Chicago I listen to
12 music through my neckneckloop and it blocks
13 out the travel sound. Any questions about
14 the train?

15 Okay. How many of you have heard, wow,
16 deaf people can drive?

17 (laughter).

18 Strategic seating. If you have the
19 opportunity to pick to drive or to pick to be
20 a passenger it can depend, some people, if
21 their left ear is the side that has the
22 cochlear implant they tend to want to be the
23 passenger. If they are deaf on the right
24 side sometimes they prefer to drive so they
25 can hear what is going on in the front.

1 You might consider an extra wide
2 rearview mirror. I am one of the people when
3 my children are in the car with me I am
4 driving and looking in the mirror a lot so I
5 can lipread. Please, please, please do not
6 text and drive or e-mail and drive.

7 If you are in a car and it is dark,
8 consider turning on the light if you need to
9 lipread or if you need to have a short
10 conversation.

11 Assistive listening devices, when I
12 still had my body processor I remember the
13 microphone. You guys remember the microphone
14 you stick in the processor and then you could
15 pass it around to people. When I still had
16 my body processor, my daughter at the time
17 was probably two, I would take that thing and
18 chock it in the back and she could talk to me
19 in the car and it was a lot easier to listen.
20 If you have a FM system, that is another
21 really great tool for using in the car. And
22 who is the audiologist that is here?

23 AUDIENCE MEMBER: Here.

24 TINA CHILDRESS: If there are people
25 that have questions about FM, I can answer

1 and you might consult an audiologist but the
2 FM system is a great way to be able to hear
3 better in the car. It also ensures that only
4 one person speaks in the car at a time. I
5 call it the I got the conch. So only one
6 person can talk in the microphone so that it
7 makes sure there are not a whole bunch of
8 people talking at the same time.

9 Here are some examples of the assistive
10 listening devices I was talking about. You
11 can use that lapel microphone. All of us
12 with implants should have got an auxiliary
13 cable or lapel microphone with cochlear
14 implants. I remember doing auditory training
15 for my first ear, my first side was here on
16 the right and I had a body processor and I
17 remember trying to listen to books on tape in
18 the car and it was really noisy. I figured
19 out that I would plug in the lapel microphone
20 and then I would clip it to my pants because
21 the speaker was right there in the car door
22 and it made the sound a lot louder and a lot
23 clearer. So if you like to, if you are
24 driving along and you want to do talk radio,
25 you might consider something like that.

1 There are even loop systems that you can get
2 for your car. So what they have is a
3 physical wire that you put on the inside of
4 your car and someone would have a microphone
5 and you switch to the T-Coil program on the
6 implant or hearing aid, and you would pick up
7 that signal. So there are lots of different
8 options in the car. When I talk about the
9 neckloop system, this is what I am talking
10 about. (indicating) There is one where
11 there is actually a cable that plugs into
12 something like an iPod. Or this one is
13 Bluetooth and so that can talk to my phone
14 and I can go answer it.

15 AUDIENCE MEMBER: Here in New York does
16 it have to be hands-free when you drive?

17 TINA CHILDRESS: Yes. This is a nice
18 option to have. Some people prefer to have
19 ear hooks. Personally, I do not like them
20 because there is a cable and they fall off.
21 I prefer the neckneckloop. You have to
22 switch to a T-Coil program. Any questions
23 about the car?

24 What to pack? I always assume luggage
25 will be lost. If it is important, I have it

1 on me. I ask myself, what do I need to keep
2 my implant going. I know people carry spare
3 parts or extra batteries but once again
4 assume your luggage will be lost.

5 If you have extra cochlear implant
6 equipment, this might be things like a
7 charger. I know people that when they go
8 camping they want to charge their batteries
9 so there is a car charger attachment so they
10 can charge their batteries in the car. If
11 they go camping there might not be
12 electricity. Any type of cables or ear
13 pieces. When I went to the Philippines, I
14 made sure I had a lot of extra equipment with
15 me. Same thing goes for hearing aid
16 equipment. Some of the hearing aids now are
17 using rechargeable batteries. So once again,
18 carry those with you. The ear mold blower,
19 that's to blow out any kind of condensation
20 in your ear mold. And I always carry, how
21 many use a drying system for cochlear
22 implants or hearing aids? Some of you do.
23 Some of them are electronic that you have to
24 plug in and some are like a bag or a
25 container with a screw-top lid you can use.

1 If you are going to be travelling, and this
2 goes for anything electronic, make sure you
3 have the right converter to go with your
4 system. I'm not sure about cochlear, but I
5 know Advanced Bionics chargers has different
6 plugs for Europe, Asia, and sometimes you get
7 all the plugs as well.

8 This is a trick that I learned and this
9 is someone that actually dropped a cellphone
10 in the toilet. If you drop something
11 electronic in the toilet or it gets wet, you
12 can use uncooked rice. This happened in a
13 restaurant. She asked the waitress if they
14 had any uncooked rice and they put it in a
15 to-go containers with rice, and she stuck the
16 cellphone in there and it helped dry out her
17 phone. And the same thing would work for an
18 implant if you were stuck in a pinch. If you
19 do not have rice, another thing that works is
20 silica packets that you get with new shoes,
21 electronics or hand bags. Do not open them
22 but throw them in a Tupperware container and
23 that can help suck out moisture as well. If
24 you do not have a drying kit, I always carry
25 Ziploc bags with me, I know I will be on a

1 boat or someplace that has a lot of water
2 happening, not so much that I will put it on
3 my head but that I have a place to keep it
4 safe. I have friends that sail and so they
5 have water-resistant hats or caps. I know
6 some people that wrap their implants in
7 bubble wrap and put it in a pouch that is
8 waterproof and only have to have the cable
9 sticking out.

10 If you travel for a long time or very,
11 very far away, consider carrying a copy of
12 your programming sheet for your implant or
13 hearing aid. The reason why I say that you
14 are going to Asia and something happens to
15 your implant or hearing aid, this way the
16 audiologist does not start from scratch.
17 They will know your settings and this is
18 something you can get from your audiologist.

19 AUDIENCE MEMBER: Would they have
20 information at your, say you go to Florida
21 and then you come back and you are down there
22 and something happens like that, wouldn't
23 your own audiologist back here in Buffalo be
24 able to converse with the audiologist down
25 there as far as mapping is concerned?

1 TINA CHILDRESS: You have to contact
2 your home audiologist and you will want to do
3 that in the presence of another audiologist
4 to let them know it is okay to give them that
5 information. The audiologist can take the
6 programming page and save it as a PDF file
7 and e-mail it to the other audiologist if
8 something happens.

9 I also recommend you should have this on
10 a card that you travel with, the customer
11 service number. When I worked for Advanced
12 Bionics, I would have clients in Asia and
13 something happened to their device and they
14 were able to contact a vendor in Asia to get
15 them a replacement part so that they didn't
16 have to wait for a part to come all the way
17 from California.

18 I so always carry a paper and pen. I
19 know Dorothy has a paper and pen. And that's
20 only just in case something happens to my
21 implant and I cannot hear so I can always
22 have a way to communicate with people. The
23 great thing about cellphones now is people
24 type back and forth also if they need to
25 communicate.

1 Power supplies, we talked about this
2 with your cochlear implant charger. They
3 should have the different plugs. So this is
4 here in the states. This is for, is this for
5 Europe or Asia? I think the long ones are
6 for Asia but make sure you have these before
7 you go. Any questions about power supplies?

8 Lodging and the ADA, lodging would apply
9 to staying at a hotel. Hotels and motels
10 under the ADA must provide you with
11 communication access. And these are not like
12 mom-and-pop bed and breakfasts, but the
13 Hilton properties, Hyatt properties, the
14 Marriott properties.

15 So what do those things look like? They
16 should be able to provide you with visual
17 alarms in your room. So if there were a fire
18 or tornado or some disaster or emergency like
19 that, that there is a way to be alerted
20 visually. There should be a way so that if
21 someone is knocking on your door that there
22 is some kind of door knocker device that you
23 put on the door that will flash. I will talk
24 about that in a minute. And hopefully there
25 is an electrical outlet so if you need TTY it

1 is right there by the phone. I know people
2 do not use TTY anymore.

3 So the hotels often have this thing
4 called the ADA hotel kit and it might come in
5 a hard shell black box or it might come in a
6 soft shell case. But when you are making
7 your reservation for a hotel, you want to let
8 them know that you are deaf and that you
9 would like an ADA hotel kit. And I am going
10 to recommend that you guys all do this. I
11 tend to carry my own portable alarm clock
12 with me. It is not huge and doesn't take up
13 too much room. The reason why is often times
14 I request a hotel kit and it may not work,
15 they may not be able to find it, or, you
16 know, something is going wrong and it does
17 not work. I am just paranoid and I always
18 like to have a backup. So you want to let
19 them know that you would like to have this
20 hotel kit. And inside this are things like a
21 vibrating alarm clock. Here is the visual
22 smoke alarm. This is the door knocker that
23 you stick on the door. Now each hotel kit
24 may vary a little bit, but at the minimum you
25 should have the alarm clock that vibrates and

1 that has a visual alarm. The TTY is so
2 obsolete now that most people do not use
3 them. But they are often included in these
4 kits because the hotel staff doesn't know any
5 better. What were you going to say?

6 AUDIENCE MEMBER: First of all, if you
7 stay at a Holiday Inn or Marriott, they will
8 know what you are talking about. They are
9 wonderful. But if you stay at Johnny's hotel
10 on the highway, not so. I have found that,
11 like you said before, tell them when you
12 check in and say something, I am hearing
13 impaired and if, heaven forbid, there is a
14 disaster you better let me know or I will fry
15 in my room. And I will sue you. But they
16 really ought to know where you are coming
17 from.

18 TINA CHILDRESS: And I will talk about
19 that in a minute, too. The kinds of things
20 you want to tell them. Sometimes they will
21 say I will put you in the accessible room and
22 that means the shower that you can roll your
23 wheelchair in so that is not an accessible
24 room. But I have been in rooms where there
25 is a doorbell on the outside that will flash

1 a light which is kind of nice. And they do
2 have an alarm clock with a bed shaker already
3 designated for that room. So they have
4 provided me with access. If there is a
5 convention, like an HLA conference or an ALDA
6 conference like that, I know that they often
7 run out of ADA kits. Say it is not a big
8 conference, but if you are travelling with
9 ten people with hearing loss group they can
10 pull some of these kits from their sister
11 hotels. They can pull them from a Hampton or
12 Hilton, and they will say, hey, can I use
13 your hotel kit. So this is what you were
14 talking about. When you check in, let them
15 know you are deaf. I think I am a gold level
16 at the Hilton and I know it is in my profile
17 that I am deaf.

18 If I know there is bad weather coming, I
19 actually will say, can you please put my name
20 and my room number on a sticky note and put
21 it on your computer so that if I know that
22 something possibly could happen that really
23 quickly they will know do not forget to go to
24 room 204 because Tina Childress may not hear
25 me.

1 Consider not using the bolt lock on the
2 door. So you go in the hotel room and you
3 can use that bolt lock, and the reason that I
4 say that, if there was an emergency in the
5 hotel, that is going to be a barrier for them
6 to get into the room quickly. They have a
7 tool that they can use to open it, but we
8 want things to move fast so consider not
9 using that.

10 Consider giving them permission to enter
11 your room because if you are deaf when you
12 take off the implants at night it does not
13 matter how loud they knock, you are not going
14 to hear them. There is not a way for them to
15 get ahold of you in an emergency. Give them,
16 consider, depending on your personal
17 preference, permission to come in your room
18 in the event of an emergency to let you know.

19 When I travel with co-workers I always
20 give them an extra key. Just so that if
21 something happens they can also get into my
22 room.

23 Hotel keys, know that, if for whatever
24 reason you put your implant in your purse or
25 you have an extra head piece, it will

1 demagnetize those hotel cards quicker than
2 anything. And you will get up to your hotel
3 room and when you try your key it will not
4 work and you will have to go back down and
5 get a key. So keep your magnets far away
6 from your hotel keys. The same thing for
7 your cellphone carrier. There is usually a
8 magnet on your cellphone carrier to clip
9 things closed. If you put the key next to
10 the magnet, it will also demagnetize.

11 AUDIENCE MEMBER: What about the remote?

12 TINA CHILDRESS: For the cochlear
13 implant? Remote should be fine. That is a
14 good question.

15 Like I said, consider bringing some kind
16 of backup if you like. I know some people
17 will use their cellphones as a backup alarm.

18 Getting closed-captions on TV in a hotel
19 can be tricky. There are hotels where some
20 channels are digital and some channels are
21 analog and now with flat-screen LCD
22 televisions and cable boxes, it is tricky to
23 get closed captioning to work. But you have
24 every right to tell the front desk you want
25 closed captioning on the television.

1 The other thing to know, often times in
2 hotels they have a universal remote control.
3 And if there is not CC, closed caption option
4 on that universal remote they might have one
5 in the engineering department where the
6 janitor is that goes with that particular TV
7 where you can set the closed captioning. But
8 I have been in hotels where it just does not
9 work because no one asked. And it is usually
10 with a new cable system or satellite or
11 whatever. Any questions about being in a
12 hotel? Did you have a question?

13 AUDIENCE MEMBER: Yes. I noticed the
14 captioning part, excuse me, ladies, depending
15 on what channel you are watching, sometimes
16 you cannot read it because it goes by too
17 fast.

18 TINA CHILDRESS: Right. Different TV
19 systems have different captioning and the
20 same goes for cable boxes definitely.

21 Let's talk a little bit about
22 emergencies. Some states have a specific
23 code that would be on a driver's license. If
24 you happen to be pulled over by a police
25 officer or if you are in an accident and they

1 read the license plate, it indicates that you
2 are deaf or hard of hearing. It is your
3 choice to put that on there or not, but each
4 state has a section about people with
5 disabilities.

6 There are certain towns that have an
7 emergency contact database. What that is, in
8 the case of like a weather emergency or
9 something like that you would get an e-mail
10 or text to let you know that something is
11 happening in the area. Where I live,
12 depending on how the wind is blowing, I may
13 or may not hear tornado sirens and we get
14 quite a few warnings in Central Illinois. So
15 I appreciate getting texts or e-mails because
16 I always have my cellphone with me.

17 There is sometimes someone told me
18 caduceus sticker. Caduceus is just a medical
19 sign. When you go to the driver's license
20 facility, ask them if they have a caduceus
21 sticker and you can put it on your driver's
22 license. And if you are not able to speak or
23 if you are unconscious, the emergency
24 personnel can pull out your driver's license
25 and they see this sticker and they will know

1 to look for a medical problem whether it is
2 an implant or not.

3 AUDIENCE MEMBER: I have a question that
4 just dawned on me. I was going to fill out
5 an enhanced driver's license application and
6 it said if you are deaf, let them know. I
7 was afraid to do that because I didn't know
8 if they would give me an enhanced driver's
9 license. What is the purpose of that?

10 TINA CHILDRESS: Probably just more so
11 if the cop knows if they are trying to yell
12 or talk through the window or from behind
13 that the person is not answering that it is
14 because they cannot hear, not because they
15 are ignoring them or doing something fishy in
16 the seat.

17 AUDIENCE MEMBER: I don't know if you
18 understood. When you fill out the
19 application for an enhanced driver's license,
20 it said if you are deaf, let them know, let
21 them be aware of it, or let personnel know.
22 And I don't know why that was.

23 TINA CHILDRESS: So they might call you.
24 I don't know. I'm not sure.

25 AUDIENCE MEMBER: I didn't hand in the

1 application. You are supposed to let them be
2 aware of it. I was afraid to do that to get
3 an enhanced driver's license.

4 TINA CHILDRESS: It used to be that if
5 you were deaf and you had a hearing aid, you
6 are required to wear it. That's what that
7 check box is for. Because if you are driving
8 and you cannot hear the sirens, it will come
9 up on your record and then they would know.

10 AUDIENCE MEMBER: Okay. I will go get
11 it then.

12 AUDIENCE MEMBER: Especially for me, I
13 have to have the-wide mirror. In Erie
14 County, and I don't know which department, I
15 think it may be social services, they have
16 this card that you can request that says I am
17 deaf, okay, so that if you get pulled over,
18 you can show the police officer that you are
19 deaf. So that they do not shine the
20 flashlight in your face. I would try to get
21 that for the website or the newsletter so
22 that if that comes up.

23 TINA CHILDRESS: That is especially
24 important for people that only use sign
25 language and do not talk. Sometimes the

1 police officers feel threatened because they
2 see arms flailing and they do not understand
3 that it is a deaf person trying to
4 communicate with them. You always hear these
5 horror deaf stories of persons in handcuffs
6 that cannot communicate and they are not
7 given an interpreter and so I think that is
8 why some of these designations on the
9 driver's license are happening so the cops
10 know that there is a reason why the person is
11 not responding or arms are flailing.

12 AUDIENCE MEMBER: I received my second
13 cochlear implant a year ago in December.
14 Ever since then I considered doing something
15 that I have not done, it is the bracelet that
16 would say deaf, have cochlear implant,
17 hearing impaired and I think that would be
18 great. Okay. You were going to do that
19 next. So it would make sense. I live alone,
20 too.

21 The other thing I want to mention, at
22 least in Niagara County, there is a
23 refrigerator envelope that if it is red, it
24 has a magnet and it does not only have about
25 being deaf, it has that -- the paper is

1 8 1/2 x 11 but it folds small and all the
2 police and emergency people, maybe it is New
3 York State, but they all know that when
4 something happens in a home, go to the fridge
5 and hope that people have completed this. It
6 is a wonderful thing to have. It is a good
7 thing to find out if your own county is doing
8 it, at least here in the state. It is called
9 My Life File and if anybody is from the
10 Cheektowaga area, you can get it from the
11 Cheektowaga office or police department
12 because they delivered it to the houses in
13 our area.

14 AUDIENCE MEMBER: I just wanted to let
15 you know also, my daughter is hearing
16 impaired, and that they requested us to call
17 the police department and the fire department
18 to tell what room she is in so they are aware
19 of our house so it is registered that at our
20 house it comes up we have a deaf child, what
21 room she is in for all purposes. So all of
22 you should be registering so they know what
23 room you are in and your address and it will
24 come up on the file as soon as there is an
25 emergency at your house.

1 TINA CHILDRESS: That is a great idea.

2 AUDIENCE MEMBER: You can also call your
3 fire department and tell the fire department
4 and they usually have a sticker you can put
5 on the child's window and the firemen look
6 for that sticker if there is anything they
7 have to do there for them.

8 AUDIENCE MEMBER: I have seen the same
9 thing for pets. Yes, there is a dog here or
10 something like that.

11 AUDIENCE MEMBER: There is a sticker
12 that goes on the window or door in the event
13 of an emergency.

14 AUDIENCE MEMBER: I was going to
15 say they moved away from stickers because
16 people would know there are kids in there.
17 So they did move away from that because they
18 know what room a child is in.

19 TINA CHILDRESS: Good one.

20 So how many people have any medical
21 devices that says they have cochlear
22 implants? I don't either. But you have the
23 patient identification card you can get from
24 the cochlear implant. When I travel and I
25 have my wallet, you know, if something were

1 to happen and I know they will look for
2 identification, the first thing they will see
3 is that card before my driver's license. I
4 actually put my driver's license in the back
5 because I want them to see this cochlear
6 implant medical card first.

7 AUDIENCE MEMBER: Are they doing
8 anything to educate people that you have to
9 deal with? I mean, it is so ridiculous. It
10 seems every time I go over the bridge to go
11 to Canada, it is not Canada so much, but a
12 lot of times in America they will go like
13 this, you know, they whisper.

14 TINA CHILDRESS: I beg your pardon?

15 AUDIENCE MEMBER: They whisper. I
16 purposely lower my voice so if I lower my
17 voice more than theirs they speak up. And
18 then they tell you if you do not speak
19 clearly, you will not get an answer from me.
20 And I say I am deaf, finally they get the
21 idea to finally speak clearly. I cannot deal
22 with mumbling. You know.

23 TINA CHILDRESS: Sorry. And it could
24 be, I see you guys altering things in your
25 wallet to change everything. That is a trick

1 I always put it in front before my driver's
2 license.

3 Now medical jewelry, there is cute
4 things you can get. It is not just a boring
5 bracelet or necklace. There are sites where
6 you can get it with jewels or whatever. I
7 saw you can, I saw this on a watch, there are
8 watches where all of your information is on
9 the back. Some people if they have medical
10 needs carry a lot of medical information on a
11 thumb drive. Where you can have your medical
12 information. And of course you want that
13 close to you. If you want to look and see
14 what your options are, but if you google
15 medical alert jewelry you will come up with
16 different websites with different options.

17 Another thing that I have is this
18 emergency medical identification card. This
19 is the website for it. What I like about
20 this card is that I can put as much
21 information on here as I want. I have found
22 that some of those medical identifications
23 really limit you to a number of lines or
24 amount of information that you have. So
25 let's say you are not only deaf, say you are

1 allergic to peanuts and penicillin or all
2 these different things, these are great. So
3 I have my name and my name is Maria, that's
4 who I am. It has my name and information and
5 I can put emergency contacts and put who my
6 physicians are and I have -- it says deaf,
7 uses cochlear implants to hear. Allergies, I
8 am allergic to penicillin and Aspirin, but it
9 says bilateral cochlear implants, no MRI and
10 no monopolar cautery. All of the things like
11 that can go on the card. All you do, it is a
12 form you fill out and print it and you are
13 done. And it is free and it is a nice
14 additional thing to have in your wallet. So
15 these are things you want to include if you
16 are deaf or hard of hearing, that you have
17 cochlear implants or hearing aids.

18 And then specifically for implant
19 recipients, no MRI, no monopolar cautery.
20 These are the same things you have on that
21 card. You want to have the name of the
22 cochlear implant surgeon and clinic.

23 Funny story, when I got my first
24 cochlear implant, in that week when you are
25 healing and waiting for the incision to go

1 down before you get hooked up, I was in a
2 wedding and I was a bridesmaid for a woman
3 who was getting married in her home. And I
4 get to her house and I am walking her dog to
5 help her out because she was all crazy. And
6 she lives on this beautiful block and there
7 were all these trees and there also all of
8 these cages all over where they were living.
9 I thought, what's up with the cages. And
10 apparently there were a bunch of squirrels in
11 the neighborhood and they were trying to
12 catch these squirrels and get them out of the
13 neighborhood before this wedding. It is kind
14 of like Steel Magnolias where the birds
15 started attacking the house. And I am seeing
16 all of this and then all the sudden something
17 hits me in the head, and I looked down and it
18 was like an acorn, and I thought it was a
19 squirrel that was really, really mad because
20 all of the cages. And later that day I am in
21 the rehearsal and we are getting lined up
22 getting ready to rehearse for the wedding and
23 I felt something wet and it was blood. The
24 nut hit me exactly on my incision and it
25 split open my incision and I had to go to the

1 emergency room. Now head wounds bleed a lot
2 and it is really, really hard to stop it. So
3 the emergency personnel wanted to use cautery
4 to close my incision and I said you need to
5 call the cochlear implant surgeon and talk
6 this through. So that is one example or one
7 of the reasons that it is important to have
8 the cochlear implant surgeon, have their
9 contact information because you might get hit
10 in the head with a nut.

11 (laughter)

12 After that I had nicknames like squirrel
13 girl. And nut case was always a favorite
14 one.

15 (laughter)

16 A lot of cellphones now have emergency
17 contact fields that are built in the
18 cellphones. In your cellphone you might have
19 a name that says I C E and that stands for In
20 Case of Emergency. That is where I enter
21 information like my husband, who would you
22 contact in case of an emergency. Would you
23 use voice mail, text, e-mail? A lot of
24 people have On-Star things. On-Star is great
25 if you can hear what they are saying. I know

1 people that have On-Star, they do not like it
2 because if something happened they would not
3 be able to communicate with the operator.

4 Okay. Here is a quiz. Any questions?
5 Did you guys learn something?

6 (laughter)

7 Okay. True or false questions.

8 1) Question: It is better to leave
9 accessories in checked baggage? That's what
10 they take and put it on the belt. Do you
11 want to leave it on there?

12 Answer: No, leave it on the carrier.

13 2) Question: If you run batteries, does
14 that affect the volt or processor?

15 Answer: It is more the processor. So
16 it does not affect batteries. I would keep
17 the batteries because if you need them you
18 want to have them with you.

19 3) Question: Power suppliers are
20 universal around the world?

21 Answer: That is false. You have to
22 have specific ones. You want them around.

23 4) Question: When you put stuff in the
24 carry-on bag that goes through check, too.

25 Answer: That goes through a different

1 machine that is not as powerful as the one
2 that checks your bag and that is okay to put
3 on your implant and batteries and stuff.

4 5) Question: You can walk through a
5 metal detector with your ear-level processor?

6 Answer: Yes.

7 6) Question: All hotels have ADA kits.
8 They know where they are and how they work.

9 Answer: No. That is false.

10 7) Question: All cochlear implants are
11 MRI compatible?

12 Answer: False. I did talk about this
13 that much, but for those of us that have
14 cochlear implants before 2005, I have two
15 different generations of technology. I have
16 C-one implant and I have a different one on
17 the other side. On this side all of the
18 internal parts and the magnets are all housed
19 in ceramic. If I needed to have a MRI, they
20 would have to take out this whole implant for
21 me to have a MRI. If I only have the implant
22 that I have on this side which is the 90-k,
23 the tiny magnet is up here and the surgeon
24 can do a quick procedure where they just make
25 a small incision and can pop out the magnet

1 and you can do the MRI, they put the magnet
2 back and sew you up, pressure bandage and you
3 should be okay.

4 So there are some cochlear implants that
5 are MRI compatible and it is usually the
6 newer ones, but if you have any, any, any
7 doubt, definitely talk to your cochlear
8 implant surgeon.

9 8) Question: It is a good idea to keep
10 your medical ID card next to your driver's
11 license?

12 Answer: True.

13 9) Question: Assistive listening
14 devices are a great way to hear in noisy
15 environments?

16 Answer: True.

17 I gave Joe a copy of this presentation
18 in PDF so if you guys do not want to write
19 down websites and all of that contact Joe and
20 he can get that to you and feel free to share
21 that with anybody. I am happy to share this
22 information and thank you so much for your
23 attention tonight.

24 (Applause)

25 >> I see this happening in college

1 classes all the time. People take out their
2 cellphones and take a picture of the screen
3 instead of writing everything down.

4 Thanks, guys. Pizza time. Great job.
5 Thank you.

6 JOE KOLIS: Before we go on to the pizza
7 I want to thank Tina for coming. Great
8 presentation as always. Thanks for coming to
9 Buffalo in November on the last day. The
10 pizza is here and Gail will get it all set
11 up. We also have door prizes that Sister
12 Dorothy will take care of. Please join us,
13 hang out for awhile, there is plenty of pizza
14 so feel free to join us. Thanks.

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