

Wed, Mar 21, 2007 HLAGR Walk4Hearing Kickoff at Noto's Old World Italian Dining

The Walk4Hearing is a nationally coordinated effort to increase awareness about the causes and consequences of hearing loss and to raise funds to provide information and support for people with hearing loss.

Chris Jacques: Hello everyone. You can continue to stand in line while I talk for a few minutes. I am not the featured speaker so it doesn't matter if you hear me. I am Chris Jacques and I am the current president of the HLAGR. Welcome tonight. We hope you get information and have fun. Please take the balloons and move them to the outside walls so that everyone in the back can see what is being typed up front.

Okay, that is much better. Again, thank you for coming tonight. We have for tonight several things to go through. First, I will give some orientation. Some of you are not hard of hearing. So you may not know about all the technology that we have. First of all we have Cheri. She is typing all that I say. I promised her I would talk slowly, which I do well. She is our captionist and comes to all the meetings so those with real difficulty can hear what is said.

Guest: can the screen go to the top?

Chris Jacques: Is that better? Okay, thank you very much. The second technology we have here is that we have a loop system. People with hearing aids which are relatively modern have a system built in that is called a t-coil. It's an antenna that picks up what I say on the microphone, sends the signal through the wire in the room and relaying the signal to the hearing aid; inside the hearing aid you can hear what is being said. It acts like a radio receiver. Put your t-coils on to hear me better. So much for that.

I would like to thank a number of people and organizations that pulled this together. We have three major sponsors: Huntington Bank, do we have a representative from there? We have the Hearing Clinic. Thank you very much. And we have Noto's Italian Dining who supplied the room.

We will get a bit more later. We had all the other sponsors on the screen when you first came in and you can look at that later. You can find the other sponsors at that time.

I will turn it over to Vic Krause, who is our founding or re-founding father of the organization. This organization started years ago and faded a bit and he got us started again three years ago. He will say a few words.

Vic Krause: Thank you very much. I am not here to run for office. Welcome and thank you for being here. Many of you have participated in the HLAA activities. Before I tell a bit about the HLAGR I want to tell you that I have a sheet up here with the teams listed. My team is the Krause House team. I have five of my grandchildren on my team. For all the grand parents here, I created a personal website with all the photos. I want to introduce four of the five right now: Alex, Natalie, Lisa and Fetzer. Thank you. They know how much I expect them to raise. They can talk to their parents and friends and some have already committed to fundraising.

I will tell you a bit about the organization. The national organization is non profit and its mission is printed on the brochures. Its mission is to provide information, education, support, and advocacy for

hard of hearing people. It's marvelous. They have a membership for \$25 a year. You can receive their monthly magazine which is wonderful with great articles dealing with hearing loss. They have state chapters and over 200 local chapters. 250, Ronnie [Adler] says. Sometimes hard of hearing people have to repeat the numbers. We are proud to be one of them.

If you look at the brochure it tells more about our mission. We have monthly educational meetings on the second Wednesday of each month. They are held at Metro Health Hospital. We are not only helping people, we help ourselves. I hope you are on the mailing list. If you are not, we will make sure you are so you get postcards prior to each meeting. Nancy Cluley is our program chair. We have an exciting fall season. We will move to Metro Health Hospital's new campus. We will have a conference room with the hearing loops installed. Watch for the move and the meetings. There is no fee to what we do. We do ask for donations once in a while but come to a meeting. That is all I have to say.

Chris Jacques: Vic has been an inspiration for us. He recruited most of us. I want to introduce Marilyn Knol who is the walk chairman for this year's walk.

Marilyn Knol: I would like to thank the academy....*(laughter)* Thank you all for coming. What we do want to do is thank all the people who have put together the local chapter and the kickoff. We met Vic Krause and Sanford Freed, our current president.... I mean that is Chris Jacques. Sandy is the treasurer. Joel Westmaas in the back has been instrumental in putting together the packets and raising money. Nancy Cluley and Hannah are over here. Did Dorothy DeRuiter come in? There she is.

All of those multiple mailings came from her. Thank you to all of you for coming. We want to take a few minutes now to give some background on our experience with hearing loss and the association. I am lucky; I am hard of hearing and use a hearing aid but it's hidden behind my hair. I have Meniere's disease. What happens with that is that you have incidents and a lot of people have dizzy spells or lose their hearing suddenly. In 1977 I lost hearing in one ear and in the other in 2002. My appreciation goes to the Hearing Clinic for helping me through it.

At first I motored along with one good ear. What I know today is that it's much easier when we use the equipment. If you sit on the border on whether it's good or not, it improves your quality of life a lot. When the second hearing loss happened, I went through the weekend but I went right back to work on Monday and called the Hearing Clinic, who really helped me. It takes months to get them *[hearing aids]* both to work, but the thing with hearing loss is that we can go day to day being hard of hearing and struggling. Or we can step up and be a part of organizations like HLAA and the Grand Rapids chapter to improve our lives and those around us.

That is what the walk is for. We want to raise awareness of all that the chapters are doing, both locally and nationally. You will see my team, Marilyn's Merry Mega-Milers. Cathy and Sherri in Lansing are on that. I hope for more of my friends to also join me. We encourage all of you to participate in the walk.

I work for Metro Health Hospital and want to say my appreciation for them and the gold sponsorship and the looping for the monthly meetings. When we have work meetings there I also take advantage of it. We are excited for the possibilities in the new campus too, in looping common areas, like maybe rooms and registration. I would like Nancy Cluley to spend a few minutes on the HLAA and her experience.

Nancy Cluley and Hannah: I just found out today that I would be talking so I am winging it. I am not

hearing impaired but someone very special to me is—my daughter Hannah. She is our second child but our first with hearing loss. She was 2 when we discovered she had hearing loss. We went to many doctors before we knew. We have a great resource, Shawnee Park for the Oral Deaf. It's emotional for me. I was looking for a resource to help me cope with some of the things that Hannah is involved with.

This organization has been a blessing for me. I have met passion and been educated. I try to get her to use the loop system and I don't hear what she hears or does not. I reach out to people without hearing loss who have wives or children with hearing loss and encouraging them to get involved.

This was helpful to me. Jim Parker, the retiring principal there at Shawnee Park, turned me on to this. I want to help Hannah any way I can and this is a lifeline. Vic Krause has an energy level I aspire to. We have been to the State Capitol where we got out on the floor with his cronies to represent the deaf and hard of hearing.

The walk...Hannah, is there anything you can think of that helped you?

Hannah: not really.

Nancy Cluley: please give it consideration for resources that you can tap into.

Chris Jacques: I would like to mention that last year Hannah was a featured speaker at the meeting one month and she gave a compelling story. I couldn't be there that night but I was in tears as I read the transcript. I would like to mention that I lost my hearing at 5 years old, I also have Meniere's disease. I am lucky that it manifests itself as only dizziness for me. Most people with Meniere's have a slow loss of hearing. Marilyn Knol may be in that group. Being hearing impaired is a struggle not only for me but those around me as well. One thing that I found with this organization is that we give strategies for those with the loss and those who interact with them.

I was raised as a scientist and thought I knew all that went with hearing loss but when I got here I learned I only know about 2%. I get all charged up about it. I am starting to grow. It's been a great experience and I want to go out and share the experience with others.

I forgot my notes tonight and had a list of all the sponsors so I have to apologize to those I forget. I do want to say that we do have a display from HARC from Kalamazoo. They have all kinds of assistive technology. It's so cool. *[Poster handed to Chris]* Now I have my notes.

We have already talked about Metro Health Hospital. Channel 13 is a sponsor. Central Interconnect. If you are from the organization, please stand up. Thank you very much. I did not see a television camera so I assume they are not here. Huntington Bank, the Hearing Clinic, stand up again. Canteen Services who will help at the walk. AVA Hearing. Hearingloop.org Davenport University. Grandville Ear and Hearing. McDonald Audiology. Mercantile Bank. The American Academy of Audiology. HearNow. Cochlear....These are all national sponsors.

Then we have a lot of individuals as well. I would like to point out that Sanford Freed's wife made all the cute shoes *[table centerpiece]*...She is a cobbler on the side. No, she bought them but it's very clever. Did I forget anyone?

I want to give you some idea of what happens to the money we raise. We do have a group of angel sponsors that help take care of the monthly programs, but this walk will allow us to expand even more. Some areas that we will look at with the money we bring in...I don't know how much that will be so I

don't want to promise a million, but we will look at three different areas.

First, we will put together an assistance grant to help people who need assistive devices that are very expensive. Second, we will also look at aural rehabilitation. It's a combination of speech reading as well as brain retraining. It takes a while for the brain to retrain itself to hear through the hearing aid. It also affects the learning ability. It's very important to be able to work on all aspects. This new aural rehabilitation program will take care of that.

Third, when we look at the population we see the hearing loss in three groups: 65 and over, which is about 33% of those in the group that are hard of hearing. The working group from 20-65, 10% of the group is hard of hearing; the children also have a 10% hearing loss rate. What we would like to do is target all three groups.

Just through the general interest we have gotten more attention from the 65 and older group, but most of us on the board are in the working group. Now we go to why you are really here. From the national headquarters, I will introduce Ronnie Adler who will talk about the information in front of you.

Ronnie Adler: Hello everyone. Can you hear me? I don't want to strain my neck so I will lower this. I am from New York so if I talk too fast, tell me. Thank you. Hello. I am very excited to be here. I flew in this afternoon and I am very excited about the walk. Your walk will have at least 200-400 people at the walk if everyone here gets involved and invites their friends. The walk multiplies in many ways.

First I will talk briefly about me. I have been involved with SHHH since 1988, which is now HLAA. I was diagnosed at the age of 5 with hearing loss. My mom either had toxemia or I had a lot of ear infections. In those days there were not hearing screenings like today. I was the youngest of four. I was a good bluffer and got away with hearing loss until I was 5 years old just by reading lips.

I have been involved since 1988 and it has changed my life. I met my husband through the organization and it really helped me to blossom. I am from New York and now live in Philadelphia with my husband. I was hired by the HLAA 5 months ago to coordinate the walk. It started last year with the walk. Steve Lennon had been doing a lot of walks prior to the Walk4Hearing. We hired him and we wanted to branch out just like the American Heart Association. We had 6 walkathons last year.

We did not think we would make more than \$25,000 altogether. But we raised \$17,000 just on our walk and at the end of the walk we raised \$48,000. Just for Pennsylvania. Altogether we raised over \$300,000. We had a walk in Houston, Rochester, San Francisco, and other cities. We have 9 now in the spring and some in the fall. We hope to raise \$750,000. We are so excited.

It's unbelievable how the program is expanding. We have Boston, Chicago, Atlanta..... Colorado, southeast Michigan. In addition to the 17 walks I still get calls and e-mails about starting more walks. I say hold it, that is enough for this year. It's getting all over the map. It's phenomenal. It's just like the Breast Cancer walk. You can talk about the Walk4Hearing. It's going to happen. That is what we want.

Now, I will try to read my notes. One of the things I want to talk about is team building. It's important for you to create a team for the walk. What I really recommend is that if you have a chapter of 20 I don't recommend one team for the whole chapter. Each person creates their own. The more people at the walk, the more money you raise. If everyone has their own team with family and friends, the walk expands phenomenally.

We have 9 teams so far. Any more teams coming up? Great. We will keep track of those people and go after them. What about the back? Okay, good! Give me the names of the teams. Hannah? The Cluley Clan. There you go. Any other ones? We are “Off To See The Wizard”, that is Dorothy's team. My team is called Wild, Wild Philly. The point is to have family and friends to walk and support you. Anyone have any questions? Okay.

The next thing is the walker recruitment. Try to get people to walk for the team. I will go over the whole packet but the money collection envelope has a list of all the national sponsors. I know when we read the sponsors before we said “blah, blah, blah” but they are not blah, blah, blah. We have big sponsors. We are also working on getting more national sponsors for the walk. Think out of the box. Coca-Cola for instance; get some big companies so it looks like big support. Not everyone knows Cochlear. We approved many sponsors as locals as well. Many companies set up a local sponsorship.

I just emailed someone who got two big sponsors in California. If you think of any sponsors that you know or you know someone who knows somewhere that can sponsor, please let us know about it. It's great to expand as much as we can.

Guest: I am trying to read the names. Who to contact? What is the name of the person to contact if you have an idea of someone who will sponsor?

Ronnie: a national sponsor? Or local? Marilyn Knol is the one to contact with the local sponsor information. What I am talking about is local or national. If you know someone in a big company or someone who could be a national sponsor, let me know. Focus on local sponsors for your walk.

What I will do is go over the packet. Open up the packet. We have been very fortunate that Sprint has done all our printing as a sponsor. On the left is information. There is a brochure for this local chapter, programs and services. This tells all that we do at the HLAA. We have a membership of about 10,000 people but we are not a big office. We are about 8 fulltime and a few part time people and a lot of volunteers. It's hard. We are in need of money. We have been struggling. Rocky Stone was the founder of the organization. I met him in 1992 and I walked over to him and said I was the new kid on the block. Every time I saw him he remembered I was the “new kid on the block”; he had a great memory. He is no longer with us.

The next item is the Walk4Hearing cash receipts. What it is: if someone gives you a check for the walk that is their receipt, the cancelled check. If someone gives you cash, take a square here and make that the receipt. It's perforated and you can make a receipt for it. So you get the point.

You have 10 on the paper. We can get more for you. Really, I think not everyone will ask for a receipt.

The next item is the Ounce of Prevention brochure, information on how to protect your ears. Everyone has a hearing loss journal. On the right side of the packet, there is a money collection envelope. Give one to everyone on the team. Marilyn Knol has plenty of them. I think you can get 2,500 people at the walk! You can do it!

If you run out of envelopes, it's a crisis. If you feel you need more, we will get them. The way it works is open this up, you see the information about the walk, and you put the money collected in the envelope. You can mail it to the walk treasurer or bring it to the walk. It probably saves time to send it ahead of time.

Another great tool is the website for Walk4Hearing. We just got it. It's a website that helps you set up the teams and walkers on the teams. You come up with the Cluley Clan and get on the

website.....www.Walk4hearing.org..... You put in the name or password and register as a team. You come up with your name for the team and if you are sophisticated you can put your picture in and other things. I hope my neighbor will help me to mine. If you don't know how to do it, ask a grandchild or neighbor. You can put in your own personal information.

You could say “walk for me, I will walk with my husband and son, we are trying to raise \$2,000.” If you tell everyone how much you want to raise, you will see the *[money]* thermometer go up. It's very exciting to see. For the Grand Rapids walk your goal for the entire walk is \$40,000. You already have \$16,000 in sponsors. I think you will go past \$40,000. It would be great for you to get on the website. It's really user friendly and not hard at all.

Guest: can people donate money through the website?

Ronnie: yes, there are two ways to donate. You can put in the money in the envelope and give it to Sanford Freed or do it through the website. If you are on the website and you have a team, when you start to collect money, get on the site before you walk and post all the money. That makes Sandy's job easier. If you get money the day before, put it in. If you cannot, fine, but we want to encourage you to get comfortable with the site.

Each year we will have more teams and more hits. It's our first year; last year we had problems but this year will be better. Any questions? No? You know more than I do then.

The next thing here is the map. You have the map to the walk. It tells you where it is. If you have any questions, talk to Marilyn Knol. I am sure you know where it is. The next item is questions and answers about the teams. It's important to set up teams. The more teams you have, the more people at the walk. A team can be a team of three. It's just to get more people motivated. Another thing is the team t-shirt.

I was talking to Jenna from Metro Health Hospital. She is setting up a Metro Health Hospital team. You should have a team t-shirt with Metro Health Hospital on it. It's a great way to advertise. Everyone will point at you and see who you are with. It's a great way to advertise. Sanford Freed could have one with Safecall on it. Encourage sponsors to do team t-shirts. Any questions?

Guest: can you make them any color you want?

Ronnie: sure, whatever you want! Let me give ideas. There was one team in Philadelphia called Marsha's Maniacs. She had all her grandchildren on it. We had a team that was all Army that was tie dyed. Another had splashed paint all over it. I had pictures of the Liberty Bell on mine. Maybe I will crack the bell really well, and do something surprising. Get as many on the team to wear the t-shirt.

I want to give Marilyn Knol cheap price information on the shirts. We will provide a t-shirt for anyone who raises \$100 or more. We want you to design your own for your team and when you leave you will get a national shirt. I want Marilyn Knol to have that information on companies that do that sort of thing. We will let you know. If you want to go on your own, fine. You can also do hats. One team had a school banner for the walk. We hope they bring a band this year.

The next thing is the role of the team captains. Read the roles and responsibilities. The important thing is that you need to motivate the team to raise money. You need to go rah, rah, rah. Have a competition. In some places they have incentives to push people to raise money. One man is planning to do a matching program. Whatever they raise, he will match.

The next thing is the team captain instruction sheet. It tells all you need to get for the folder. The next color, orange, is making the shirt. Come up with a really cool t-shirt that is unusual.

The next important item is the letter writing campaign. Some of you are not comfortable with that but writing your story, like Hannah's that made Chris Jacques cry, believe me if you do that money will pour in. Draw a picture with it and send it to all your family and friends. Money pours in. I wrote a story and sent it by e-mail and a couple people responded. So I did snail mail. I sent it to all my friends and family; it really works. If you take the time to write a letter and tell why you are on the walk and what it means to you, people give money.

When you get your first check, you will jump. It's the most exhilarating feeling. Each day I would check the mail and get excited. Here are samples to give you ideas. As you keep going down, you see sample letters, e-mail notes, all kinds of stuff. Here is a sample letter. We have new ones this year. I responded to my own letter while I was on the plane. Away from my computer I have my own quality time.

Anyone have any questions so far? I have 5 minutes left. The thing I want you all to do that is important..... I want you to take as many posters as possible and put them up at every library, hospital, place of worship, schools, banks, wherever you are. I keep them in my car and put them everywhere I go. My car is like my office. The same goes for Marilyn Knol. The thing is take as many as you want and put them everywhere. Let's get 500 of them up. Any questions? I did good! Thank you.

Chris Jacques: Thank you, Ronnie. Just a few more minutes and we will be all done. Now is the time I close the doors and lock them and not let you out. I want to say first when we finish that we will have tours of Noto's Italian Dining here. There is neat stuff here if you want a get together in the future. Stick around after to do a tour; you can also go to the bar.

I did miss two other people to thank. I want to thank Mercantile Bank. And the other thing is that Boy Scouts of America will help us be organized at the walk.

Right now we will pass out yellow sheets. We will have time for questions and answers in a minute. We do have a 5 minute movie we want to show as well. The movie is captioned so Cheri gets a break.

Vic Krause: A word about the upcoming Day at the Capitol. While we get the movie set up, if I can have your attention, I just want to briefly tell you about another event that is coming in May, on May 16. It's called a day at the State Capitol for deaf and hard of hearing people. The purpose of the event is to bring people together to advocate for a number of issues like hearing aid tax credit. To advocate for mandated insurance coverage. And to advocate for a number of different issues. I want the audiologists to know that the Michigan advocate, Noreen, is on the board. Last year we thought 50 people would come but we had 175 people come. We have assistive listening devices, signers, and the room is looped. I will get the information to you. The only cost is the drive. We will have a bus come to Grand Rapids if we have enough people sign up. I will get the information to you. I hope you will consider it. Howard and Nancy were there. You know. To be there and be recognized is great. May 16 is the Day at the Capitol. I will see you get more information.

Chris Jacques: we have a technology glitch so we won't see the movie.

Ronnie: we have a convention this year. June 23-24 in Orlando, Florida at Disney's Coronado Springs Resort. Anyone going? We need to get more people to go. Grab a postcard on the table. It's very exciting there and there is a lot of information. Next year the convention will be in Reno, Nevada. For

more information visit our website at www.hearingloss.org

Chris Jacques: you all have this. The first table done with the most gets what is in my pocket: a whole bunch of gift certificates for Noto's Italian Dining. While you fill it out, which should not take more than 6 minutes, we will be finished but I wanted to say that you heard that we raised \$16,000 so far in sponsors. When I look at all the sponsors for walks, we are tied with Atlanta for second place. Grand Rapids will be on the map for hearing loss in the positive sense.

Our goal is \$40,000 but based on our sponsors we should be able to get to \$50,000. Thank you for coming and listening. It's going to be a lot of fun. The fundraising is for a worthwhile cause and you will feel good about it in the end. You only have to walk, not run. We will give these gift certificates to those who fill this out fast. We have judges walking around now to figure out who is going to win. We have four here. How are we doing here?

One other thing, Dick McKinley stand up. He is from Premovation. I wanted to thank Dick for looping the room so we could hear tonight. So between Dick and Cheri everyone can hear or know what is said.

Four is the best? We got two from the table in the back. We got another from the Krauses in the back. Four up here. Three there. Hearing Clinic folks still working on it. Do I hear five? Three more back here. We have four people and all signed up at two tables! Okay, going once.

One other thing. If you did not fill out the sheet tonight, you can fill it out later and send it to us. You don't have to commit right now. In 5 minutes Tony Noto will be here to give the tour. I will call this table here the winneroops, my wife just told me to split up the tickets and have 2 winners, we have enough.

If you have any questions, we will stick around. HARC is in the back so check out what they brought. We have more brochures up here as well as posters up here. Thank you for coming!