

Transcript of Technology and NF2 from a presentation by Amanda Bergner, Johns Hopkins NF Center and NF Mid-Atlantic (June 2013)

Barbra: Hello, I'm Barbra Levin, Executive Director of NF Mid-Atlantic, and I'm so happy today to introduce our friend Amanda Bergner our friend from Johns Hopkins from the Comprehensive Neurofibromatosis Center in Baltimore Maryland. She's also the Director of Operations for the Neurofibromatosis Therapeutic Acceleration Program and member of the Kennedy Krieger Johns Hopkins Genetic Counseling Consortium.

We've asked Amanda to talk to us today about some of the advances you've been making for people who are hearing impaired.

Amanda: Yes, thank you for inviting me today and to bring some of the research we've been doing. I launched a study in the past few months about the use of technology for people with NF2 who have hearing loss. And we're looking specifically at the use of apps—applications that can be downloaded onto iPhones, iPads, or other tablets that are created to support people with hearing loss and haven't been looked at specifically for people with NF2 who not only have hearing loss, but may have other motor and functional problems that might impair their use of keyboards, being able to speak clearly depending on where their tumors are located. So we're hoping to analyze several of the most popular and well know apps as well as some of the less well known apps that are modifications of other technology used for communication that typically come with all their own instruments and equipment that people have modified on a tablet or a phone.

Barbra: That's great. So it's not a matter of reinventing the wheel, but utilizing things that are already out there that may be inexpensive and assessable to people already.

Amanda: Right, so we're not creating any new apps, or even modifying the ones that exist. Our first step is to assess and evaluate the ones that are already in existence. If we find there are several apps that already exist and are really beneficial to people we won't have to recreate the wheel, but use what's already there. We're also going to look at what they cost. Many of them are free. Many of the apps we're looking at range from \$100-\$150 to purchase. One of the reasons we want to look at those is that that is a huge expenditure and before someone purchases that we want to have some testing of that and some assurance that it will serve the purpose they were hoping before they purchase it. That would be valuable information.

Barbra: That is great. It is certainly the number 1 question we receive as regards NF2 for some assistance with hearing. So we're so pleased that Hopkins and specifically NTAP is working on this. Tell me, what can we, and the people listening to this, do to help you?

Amanda: Great, I'm so glad you asked that. One of the first things you can do, is if you have NF2, and you have hearing loss, we would ask that you go on-line to the on-line survey we have. It will be available until the middle of June. We're really delighted with the response so far, but we'd really like to

hear from as many people as possible before the middle of June. It takes about 10 minutes to fill out the survey and I believe the link is already on the NF Mid-Atlantic website.

Barbra: Yes it is

Amanda: So if people could respond to the survey. It would be really helpful and supply us with the basis for the next phase of research. And if people are in the Baltimore area from September to January (2013-2014) we're going to be doing one on one training on a couple of the apps that are looking to be the most promising. We'll be training people on how to use them and take people to a variety of settings—like restaurants, doctor's offices, outside on the street—different settings where people have difficulty communicating with others so it's one on one work for about 2 hours. If people are interested in offering their time in order to test out some of these apps we're looking at, I would be happy to hear from people about that as well.

Barbra: That is great. On this video we will put the link to the survey <http://www.instant.ly/s/-QP9e/nav#p/186a0> and any link you'd like. People can also write us: info@nfmidatlantic.org and we'll be happy to transfer that information over to you. That's wonderful because the faster we find technological solutions, the better the quality of life for everyone.

Amanda: That's how we're seeing it as well. In the interim while we're working hard on drug therapies and other things that might retard tumor growth, in the interim it's really critical that people can communicate effectively with those around them.

Barbra: On behalf of all of us—the whole NF Community—we want to thank you for all the work you're doing, and also we want to invite you back if you would entertain that and give us a follow-up on how things are progressing.

Amanda: That would be great. Thank you, I appreciate your support of the research we're working on Barbra.

Barbra: Not at all. We appreciate all you do for the NF Community. Thank you.

Amanda: Thank you.

Barbra: Take care

Amanda: Take care. Bye.