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## The Bionic Ear Association

Marcia Finisdore, Lorie Singer, Jerry Schloffman

Marcia Finisdore: I wore hearing aids for 40 years, and had a cochlear implant in the year 2000. I have been an advocate for people with hearing loss for at least 25 years and I have three hard of hearing children. Two of my kids actually qualify for cochlear implants, but have thus far not wanted to be implanted.

Lorie Singer: I have had an implant for six years. I had normal hearing until I was in my 30s, and then it went down very quickly. I wore a hearing aid for about five years, but it really didn't help me. I reached a point at work where it was just exhausting, so I was implanted. I've worked for Advanced Bionics for two years.

Marcia Finisdore: Our goal this afternoon is to give you some background about the Advanced Bionics Corporation and the evolution of The Bionic Ear Association.

Advanced Bionics Corporation is a global leader in the development of implantable high tech neural stimulation devices. Our bionic technologies include new treatments for deafness, urinary incontinence, and chronic pain. Advanced Bionics is the only cochlear implant company in the United States.

Mr. Al Mann, a physicist, innovator and risk-taker, founded the company after success with the development of a pacemaker company, Pacesetter and the development of MiniMed, a company that pioneered the insulin pump for people with diabetes. The first major product from Advanced Bionics was the Clarion Cochlear Implant.

The current president of Advanced Bionics and co-CEO with Mr. Mann, is Jeff Greiner. Mr. Greiner is a graduate of the Air Force Academy, served time in the Air Force, completed law school, and was involved originally with the development of MiniMed.

The mission of the organization is to develop, manufacture, and market implantable neurostimulation devices, bionic technologies that treat neurological conditions.

Why is this company successful? First, there is constant research and development of current and new products. The second reason is service--servicing people who need bionic technology or use a cochlear implant. For example, the first time that I needed a replacement cord for my CI, I called, and the next morning there it was at my doorstep. Third, consumers are involved in the development process. The company is constantly asking for feedback on its products and consumers are in leadership positions in the organization. The Director of Corporate Marketing and the Manager of Business Partnerships both have cochlear implants.

The Bionic Ear Association (BEA) is a natural outgrowth of a company interested in feedback from consumers, in service to consumers, and in research. The products developed reflect the needs of consumers.

Making the decision to have a cochlear implant is often difficult. The Bionic Ear Association provides mentoring, support, and resources for candidates – people resources and educational resources. Additionally, the BEA works to increase awareness about cochlear implant technology and to provide accurate information about cochlear implants.

Members in their respective states work to educate others about newborn infant screening in the hopes that educational, career and social outcomes for children born with hearing loss will improve. Early identification of babies with hearing loss should have an impact on how we view hearing loss, because we have started to see babies at three or four months of age with hearing aids and older babies with cochlear implants.

I would like to tell you how I made the decision to have a cochlear implant. Over my years of going to SHHH conventions, I went to all of the workshops on cochlear implants. I investigated them all—what they did and how they worked. My biggest fear was that I would not be able to continue to go to the opera. I was a very good speech reader. I was not uncomfortable wearing my big, clunky hearing aids. I always asked for access. But I was not hearing, even though I thought I was. At a SHHH Convention in 1998, I met an old friend—a very dynamic, energetic woman. She was no longer the woman I remembered. Her energy was gone, she was very overweight, depressed and miserable. She had lost all of her residual hearing. About a year and a half later, my dynamic, energetic friend was back to her old self. She had had a cochlear implant which she felt gave her back her life. It was time for me to have a cochlear implant

I am in awe at the opera. The arias are incredible. I continue to marvel at what I thought I was hearing before I was implanted.

Lorie Singer: I have quite a different story. I didn't realize how bad my hearing was. But I finally reached a point where I really had to do something. I went to a social worker and she took a look at my audiogram and suggested a CI. That was in December of 1995. I was implanted in April and turned on in May. I was afraid of what it was going to sound like. At first I didn't like it. Part of the process though is that you have to teach your brain how to listen, and to understand speech and that can take time. I've met hundreds of people who have gotten implants and almost all of them have felt that the implant makes their life easier.

Marcia Finisdore: We may sound like this is a perfect solution. It is not. While getting used to the very noisy world we live in, trying to make sense of conversations our brains have not heard for

years, learning the tricks of experienced users, all of these and more are invaluable assets provided by BEA members.

Members of the Bionic Ear Association help people prepare for cochlear implant evaluations. The better prepared that you are, the more likely you are going to be able to ask the right questions and make the correct decision for yourself. You can be put in contact with somebody who has had a cochlear implant wherever you live. Advanced Bionics has a team of people that work specifically on reimbursement issues. We are advocating for support for people on medical assistance (Medicare and Medicaid).

So far, I have talked about support before you are implanted. We also need it afterwards. For example, you have to practice listening. We suggest ways for you to do so. There are also assistive listening devices which are used with a CI that may be of help. We can make suggestions to help you adjust to hearing again. Picking the best phone or the best adapter and where to find these items is also some of the information BEA members can provide.

You want to stay in touch with the company that made your implant, and make sure that you get up-to-date information. We also have a team Clarion mailing list that sends out information on new developments.

Questioner: I have a Clarion and mine is not working, but also I was never told I might develop a problem with balance—which now makes it difficult for me to walk.

Lorie Singer: Jerry can answer this best. He is the Director of Professional Education of Advanced Bionics, and an audiologist.

Jerry Schloffman: There are risks with cochlear implant surgery that everybody learns about when they go through the pre surgical procedure. The hearing and balance systems are interconnected. So when you get a cochlear implant, it's possible for your balance to be affected. The percentage of people with serious balance problems is probably less than half of a percent. There are risks going into this surgery. Before surgery, we never tell any patient that they are going to be a great user, even if deep down we really think they're going to do well right away. We try not to get people's expectations up.

Marcia Finisdore: There are no guarantees in any surgical procedure. All you can do is share the statistics of what has happened to other people.

Questioner: I know that after my surgery my tinnitus went away, and I loved that.

Jerry Schloffman: Tinnitus is a byproduct of hearing loss. Cochlear implants often do reduce tinnitus significantly, but the flip side of that is every now and then implants can increase tinnitus. But most of the time it really helps.

One of the amazing things is that when the ear just sits there due to hearing loss you usually develop tinnitus. Afterwards with the implant, it will go away. And after awhile, it may be gone when you take the cochlear implant off.

Aural rehabilitation is useful for everyone. There is a trend that when an adult gets a cochlear implant, if they had normal hearing most of their life, they don't get a lot of rehabilitation because they do pretty well right away. I think that most people would do even better if they did get rehab. Children always get rehabilitation. People that have been hearing impaired a long time usually get some rehabilitation. It could be as simple as sitting with a friend with a newspaper, and having your friend read from the newspaper. Eventually they could begin covering their mouth when they read.

Lorie Singer: I didn't go for rehab until about six months after I was implanted. Vocational Rehabilitation in New York State covered it. It can be very helpful if there is any place that you can go just to get some ideas for practice.

Marcia Finisdore: I did not have rehab, but what I did do was buy a tape recorder, a patch cord, and started to read children's books on tape, graduating to adult books. I did it early, like two weeks after, and it helped me.

Jerry Schloffman: In general, the number one predictor of cochlear implant performance is how long you have had a profound hearing loss. The shorter the time, generally the better the outcome. A sensorineural hearing loss due to noise exposure is exactly the kind of hearing loss that cochlear implants are designed to help. It is actually better to have that type than one which directly affects your brain. You can contact advanced bionics at [info@advancedbionics.com](mailto:info@advancedbionics.com) or go to [www.bionicear.com](http://www.bionicear.com) for information. Thank you all for coming.

Lorie Singer is the Bionic Ear Educational Specialist at Advanced Bionics. She has a B.A. in Biology from Franklin and Marshall College in PA and an MBA from Baruch College/CUNY. Before joining Advanced Bionics in June 2000, Lorie worked for a medical/scientific/technical publishing company in NYC where she held a wide variety of positions. Since receiving her CLARION, she has spent much of her free time educating people about cochlear implants, and guiding them through the implant process. She is currently the Vice-President of the Cochlear Implant Association, Inc. Lorie has been a CLARION user for almost 6 years.

Marcia Finisdore graduated from the University of Pennsylvania School of Nursing and received her Master's Degree in Nursing Education from Villanova University. She was diagnosed with a progressive sensorineural loss 40 years ago and received a cochlear implant in July of 2000. Her hearing loss is genetic. Her three children also have a sensorineural hearing loss. She is a past president of Self Help for Hard of Hearing People, Inc. Marcia is currently working as an education and outreach specialist for Advanced Bionics Corporation. She has received numerous professional and civic awards for her advocacy efforts related to access to health care for medically underserved people and for people with hearing loss.

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