

NIDCD
National Institute on Deafness and Other Communication Disorders
Interview with Geraldine Dietz Fox
Conducted on October 24, 2018 by Kate Hallgren

KH: This is Kate Hallgren. I'm a senior historian for History Associates. Today I'm interviewing Mrs. Gerry Fox. I'm so happy to be here. We're going to talk about the history of the National Institute on Deafness and Other Communication Disorders. This is October 24, 2018. So I wanted to start by asking you, did you grow up in Pennsylvania?

GF: No, I was born in West Palm Beach, Florida, and there I lived until I was nine. Then I moved to Miami for about three years. Then I moved to Miami Beach, and that's where I resided before I got married and moved to Philadelphia.

KH: What was it like there?

GF: It was wonderful. I went to the beach every day with my mother. My father bought a little roadster when we were young, and so she put us in the car every day and we went to the beach every day. That's not a bad life.

KH: That sounds pretty fabulous. Did any teachers in school especially influence you?

GF: One I remember very well, Mrs. Daly (phonetic). I sneezed, and she gave me a medicated Kleenex, which I promptly choked on and coughed, and all the children

laughed. That was a very good lesson for me, is that she should not have done that to have people laugh at me. So it was good to how to treat people. To always keep in mind how they're going to feel.

KH: You later taught preschool, am I right?

GF: I taught school. I taught high school, middle school, preschool, everything.

KH: Did you know you wanted to teach when you were growing up?

GF: I always knew I loved children, and I was going to marry a man who I thought would be the best father in the world. So that eliminated a lot of men immediately. Until I got to my husband, then I said, "Ah-ha! He's the one." But now to get back to your question, did I know I wanted to teach? No. I was a musician. I wanted to be a musician. Teaching was something I did on the side. I always played music professionally and taught on the side.

KH: I didn't know that. What did you play?

GF: I started off at nine. I played the accordion, then I went to piano. I majored in music at the University of Miami, and I desperately wanted to work, so I graduated in two-and-a-half years, just to get out of school so I could go to work. I wanted to go to a music

school per se, and my father said, “No, you’re not going to get a rounded education with that. So I want you to go to a university.”

And it turned out he was right. One of my favorite courses were geology and botany. That kind of carried me through to my new life eventually. I gather you’ve heard of the Barnes art collection? Well, Mrs. Barnes was into horticulture, so I went to the horticulture school for three years, plus I went to the Barnes Art Foundation. So my interests have always been very varied. Music, art, flowers, everything.

KH: Wow, that’s fascinating.

GF: See, there’s time if you just, you don’t think about that, but there’s time.

KH: What did you teach later?

GF: I didn’t teach later. I don’t know what you mean by later, but I taught when I was still in school. I probably taught accordion. I got in my car and drove around to certain children’s houses, and it was fun. But I also taught in school. I taught art in school. I was really not qualified at that point to teach art, but when you’re a sub teacher you teach whatever they tell you to teach.

KH: Sometimes you have to make do with what you get when you’re a substitute teacher. Did you take part in any political activities when you were young?

GF: My father did. My father was always interested in politics. He was a very wonderful lawyer and a successful lawyer, and yet he loved politics. He felt that to work for other people who were serious about what they wanted to do in life was a very important thing, to change things. So he was my role model very young, and he used to take us to political rallies, and he ran Senator Pepper's campaign to be one of them, which was successful, to be a Senator.¹ Senator Pepper didn't lose his senatorship until 1950. So this goes way, way back, when I was a little girl.

KH: What did you think of the rallies?

GF: Oh, it was fun. You know, it's always fun.

KH: So politics was exciting.

GF: Yes. Well, my father was interested. My father was the type of man always helping other people. That was part of his being. You don't just work, and you don't just have a career in one area. I don't think he thought of it that way, but that's what he was. He was just a very generous, loving man. And a very involved man. Everybody always came to see him, and then later I married my husband. I married my father. It's the same kind of thing. There wasn't too much difference.

¹ Claude Denson Pepper served Florida as a U.S. Senator from 1936 to 1951 and U.S. Representative from 1963 to 1989.

KH: So you met your future husband, Dick Fox, in Pennsylvania after you had come?²

GF: Yes, I was living with my aunt and uncle. I was out of college, and I was working as a musician and as a teacher. Then I met him, and he asked me out and I said no, and then he came to Florida a couple months later, and then I said, "I'm sorry, I can't meet with you, my father's in the hospital." So he said, "Well, all right." That was it. So I went to the hospital and talked to my father. And he said, talking, you know, in those days you were under an oxygen tent.

And so to make conversation, I said, "Oh, you know, Uncle Bernie's friend's son called me and he wanted to go out." And my father, under an oxygen tent, said, "Are you going with him?" I said, "No, Daddy." He said, "Why? You just want to go home and sit in a chair and think about me." And I said, "Daddy, that's exactly what I'm going to. That's exactly what I want to do." He said, "If that nice young man calls you again, you go out with him." So that nice young man called me again, and we went out. Our first date was at the bottom of the steps of the hospital at nine o' clock, because that's when visiting hours were over.

KH: Wow. That is a very sweet story.

GF: That was it. As my mother always says, that's the beginning of the end. (Laughter.)

KH: He was also involved with politics as well?

² Richard J. Fox.

GF: Yes. Now we're fast-forwarding to being married. He's a successful builder, and always the same thing, loving politics, wanting people to get involved who could help the world, and he was going to help them help the world. So it was just, you know, like déjà vu. It was like marrying my father, as I said. And life was good. Life has always been good.

KH: So let's talk a little bit about, forwarding to your time teaching, and then hearing loss as a subject.

GF: Then I was married. I had been working, so I was now bored to death like the young girls are today who get married and all of a sudden there's nothing to do, or there's no remuneration for what they had had, and they stop working. So I, for lack of something to do, actually, my sister and I were on television first. I would play the organ and accompany her, and she and I would make up songs, very funny songs. We would write clever songs. We were on a show in Philadelphia called the Allen Prescott Show. We were on his show until he was let go, and then we no longer had a job.

So now I'm kind of bored again, and I started teaching school at a preschool. The children were only really up to five. One time a precious little boy named Henry Pierce (phonetic); I want to know what happened to Henry Pierce. He really lived around the corner from me, but I don't know what happened to him. Anyway, he came down with the mumps, but I didn't know that. He was on my lap. I was hugging and kissing him.

The next week, I knew he had mumps, and then whatever the timeframe was, two or three weeks later, I had the mumps.

And now I'm in bed, and the phone rings. So I picked up the phone, and nobody was there, so I hung up. Then the phone rang again, and again nobody was there, and I accidentally dropped the phone, and I picked it up with my other hand. Now I could hear, and so I went from hand to hand, thinking, "What happened here? What happened to my ear that I can't hear?"

Then I remember that the doctor had said B12 shots, and my husband learned how to give me B12 shots every day, that that would help my hearing. It never did, but that was the general idea. Then I went to Johns Hopkins, and with John Bordley, who was head of the otolaryngology department.³ And under his watch, there were some wonderful young men studying to be otolaryngologists, one of which was Bob Ruben,⁴ one of which was Jim Snow,⁵ who later became head of the NIDCD. I knew Jim because he was my doctor at University of Pennsylvania. So I was delighted that he got the job.

KH: That's fantastic. So what did they tell you when you went to Johns Hopkins?

GF: What did they tell me? Like all other doctors that I had gone to, that was it. I had lost my hearing; they were sorry; there was no cure for it. So I had to accept that, really. And then one day in the mail, I got a flyer from some place called the Deafness Research

³ John E. Bordley, M.D.

⁴ Robert J. Ruben, M.D.

⁵ James B. Snow, Jr., M.D.

Foundation, saying that they collected ear bones for an ear bank, which I think at that time was up at Harvard. They were raising funds for research. “Research? There’s a place raising funds for research?”

So one day I went to New York, and this was just tucked back here in my brain, in the back part. And I went to New York one day, and I couldn’t get this out of my mind, that there was a place raising funds for research. I know I was on Fifth Avenue, because I’d just come out of the Metropolitan Museum of Art. Don’t ask me why; I went to the phone, in those days, we had phones that were on the corner. You were too young then. You weren’t born yet. So I picked up the phone and I said, “Well, I just got your flyer.” And I said, “You’re not making enough money to cure my hearing loss. I am involved at the Pitts Academy of Fine Arts, and I help them raise funds for their students and their artworks. And I would like you to do X, Y, and Z. I want to tell you about other ways to raise money so that we can make it for research.”

And they said, “Where are you?” (Laughter.) And I said, “Well, I’m in a phone booth on Fifth Avenue.” They said, “Well, can you come down here and talk to us?” I said, “Well, I have to make a train, but yeah, I guess I could come before I make the train.” And so they said okay, they gave me the address, and I went down, and before you knew it, don’t ever ask people who want to make money for you, you ask them to be on the board. So they put me on the board. The only correction I have in there, the other thing was, they’d said the Deafness Research Foundation was head of the Government Relations Board. I don’t think we ever really had a Government Relations Board.

So from there I said to them, “I’d like to go to Washington to see if we could raise money from the government,” because somehow I learned that the government was the largest funder of deafness research. And I thought, “What are we sitting here for, raising money from people, just people-people? There may be more money to raise in Washington.” So I said, “I would like to go there on my own, with my own funds, and I’ll check around and I’ll ask questions, and I’ll come back and I’ll tell you whether it’s feasible for us to get involved in asking them to help us raise money.”

So I went, and I came back and said, “I think it’s feasible.” So then I asked them to support me a little bit with finances. They did minimum, but that was all right, that was their choice. And because I was able to, I footed the rest of the bill myself, because that was important to me now. I had a chance to get my hearing back with research. That was it. So that started it. You got me in a nutshell now.

KH: Oh, wow. It’s fantastic how you were able to translate your own experience into larger fundraising and these larger goals.

GF: Well, because I had been hearing-impaired for a long time, but with that, remember, really, right after I got married, like four years. And I never told anybody I was hearing-impaired. And when you’re hearing-impaired, if somebody laughs at a joke, you haven’t heard it, but you see them laughing, so you laugh. It’s really a crazy thing. Everybody’s okay with people wearing glasses, but they’re not okay with people having a hearing loss.

It's just verboten. I don't know how to say it. It supposedly makes you look old. So people don't really reveal that they have a hearing loss.

And so it's a struggle, and yet, later on in the game in our interview, you'll see when I started my own foundation, and then had parties to raise funds, you'll see how many people came forward and said, "I have a hearing loss." And it took all that time or took me even more time to get men to say, "Okay, Gerry. I'll go get a hearing aid now. I really can't hear."

But it took that movement of me putting out that – and people would say to me, "Why are you working so hard on this? Why are you working so hard in Washington?" I said, "Because I'm hearing-impaired." "What? You're hearing-impaired? I didn't know that." Because most people cover up being hearing-impaired very well, just by the reasons I gave you. They go along with it. They don't say every two minutes, "What did you say?" They go along with what they think they've said, or they will go along with the laughter of somebody if it was a joke. So they'll go along with that, but they don't ever come out and say, "Would you please speak up? I can't hear very well; I'm hearing-impaired." And that's kind of shocking. That's where I finally came out. I came out of the shadows.

KH: So by getting involved with the Deafness Research Foundation, the fundraising and campaigning in Washington, you decided to sort of take a more active approach and tell people you were hearing-impaired?

GF: Well, as I was working, I mean, I just went ahead and was lobbying. There's no other word for it, because I would go in, and I would take papers with facts on them, numbers, how many people were hearing-impaired in the United States, how many people needed hearing aids and didn't wear them. And I would just go in from door-to-door in Congress. I first went in, of course, to people that I knew, that I was involved with in campaigns. My husband ran Ronald Reagan's campaign in Pennsylvania, and that was a tough state to win, and he won.⁶ So I knew a lot of people from the Reagan years. Jack Kemp was a very good friend of ours, et cetera.⁷

So I started, of course, as I say, going to people that I knew, and if anybody, as I started to say before, gave me an idea, and remember, I didn't know what I was doing, really. I was a person that wanted to be cured, and I thought the way was through more money for research in Washington. I hadn't thought yet about an institute. I'm still on my research and raising money.

So I would go in to people, and especially people like Earthamae Isaac,⁸ who worked for Arlen Specter.⁹ I could go to his office, because he was from Pennsylvania. And then Betty Lou Taylor,¹⁰ who worked for Natcher¹¹ first, and then later for Tom Harkin.¹²

⁶ Ronald Reagan served as U.S. President from 1981 to 1989.

⁷ Jack Kemp served New York as a U.S. Representative from 1971 to 1989 and U.S. Secretary of Housing and Urban Development from 1989 to 1993.

⁸ Earthamae Isaac, Legislative Assistant for Health Issues to Senator Arlen Specter.

⁹ Arlen Specter served Pennsylvania as a U.S. Senator from 1981 to 2011.

¹⁰ Betty Lou Taylor served as Subcommittee Staff for the Subcommittee on the Departments of Labor, Health and Human Services, Education, and Related Agencies in 1987.

¹¹ William H. Natcher served as Kentucky's U.S. Representative from 1954 to 1994.

¹² Thomas Richard Harkin served Iowa as a U.S. Senator from 1985 to 2015.

Two women were just very willing to share information, tell me what I needed to do. One of the things they suggested was, “Get a lot of people to sign that they wanted an institute. You need to go around to the Congressmen and the Senators and have them sign and say, if they wanted to have one, if they’d be willing to vote for one.” I think that was my first step.

So I would go into an office, a Democratic office or a Republican office, and I would say, telling them about the Institute, “And can you sign my paper?” And they’d say, “Why would I want to sign on to that paper? I’m a Democrat. Why would I want to sign on to a Republican paper?” Then the Republicans would say, “Why would I want to sign onto that? I’m a Republican; that’s a Democratic paper.” Then I’d give them the name of a Democrat or a Republican who had already signed on, you see. So I’d get my friends to sign on first, because they’re different, Republicans and Democrats. So I would do that, and then if I got something like that and they didn’t want to sign, that’s how I got them to sign. Not that I got them to sign, they were just, it’s the nature of the beast.

KH: You had to be convincing. Well, I might be backtracking just a tiny bit, but I wanted to ask about your appointment to serve on the advisory committee of NIH’s then National Institute –

GF: – of Neurology, yes. Well, you were backtracking for a good reason. That started before then. I was a Reagan appointee, and then I served under Dr. Murray Goldstein.¹³ So I

¹³ Murray Goldstein, D.O., M.P.H.

served on there, and in the meantime I was still actively trying to raise money for hearing research, although hearing was on the neurology budget.

KH: I guess it was called the National Institute of Neurological and Communicative Disorders and Stroke in the 1980s.¹⁴

GF: Yes, that's exactly what it was.

KH: How did you find out that you would be nominated? That must have been a pretty exciting moment for you.

GF: I have no idea. No recollection at all.

KH: You were probably very busy. You also had a family.

GF: Yes, we have five children.

KH: So you were balancing all of this –

GF: You just met two of them. (Laughter.)

KH: You were balancing all of this with your family life at the same time.

¹⁴ The institute has since been renamed the National Institute of Neurological Disorders and Stroke (NINDS).

GF: Well, actually, I didn't start really lobbying until Michael, number five, was in the last year of high school. So I was a stay-at-home mom. How about that? And I always tell people who go to work early, "You know, you've got time. Raise your kids first." They don't like to hear this, but that's the way I feel. I really feel that mothers should raise their kids, not have anybody else raise them. Unless, of course, if financially you have to do that. Which I understand completely. But Michael would leave for the last year of high school, I would leave and go to Washington, I would come home on the four o'clock train, and we'd both get in the house at the same time because he had sports.

KH: That's exciting. Then you could talk about your days and compare. Sports and Washington can be, you know, some similarities there. (Laughter.)

GF: Right, exactly. But to get back to that last question, so I was on the advisory committee and learning a lot. In the meantime, things were moving along in Washington, because I was lobbying there for deafness research. Word got out that somebody was trying; they were going to remove the deafness portion of the Neurological Institute to a home of its own, because that was my goal, was to move it out and have a home of my own.

KH: Can I ask you a little bit about that? How did that idea come to you?

GF: That idea came to me because of all the money that the Institute of Neurology was receiving, and I'm going to shorten the name. Deafness affected more people than heart and stroke, et cetera, all the things that they were covering, and when I found out that, it's

not fair, whatever you want to say, I said, “Well, then we should move it out and we should take that portion of the money that we’re getting from the government. We could do that and start a home of our own.”

Again, I was helped by Earlene Elkins, who worked at that institute. Whether I should mention that or not, I don’t know. But Earlene was fabulous. She was the one who told me that, who alerted me to the fact that we were getting a portion of the money that was not equal to number of people affected by hearing loss and deafness. You never tell people that like me, because then you say, “What do you mean?” (Laughter.) “Go back to work,” you know.

KH: So it was pretty clear to you that rather than fight within the institute for more funding for deafness or hearing loss research, that you needed a new institute of your own?

GF: Well, that’s just the way that I felt. I felt that if we could get that much money within another institute, if we had our own, we would not be vying with anybody else. We could then present materials saying how many people were affected, how many people needed hearing aids, and then how research could help. What’s the final line? What are we aiming for? So of course I had to sit in these meetings and hear discussions like, “Dr. Goldstein, I hear that they may take deafness out of our institute.” And I would sit there with a straight face. And he would say, “Oh no, that’s not going to happen.” And of course I knew it was going to happen shortly, but I would have to just, people would be looking at me and I would have this mask on my face.

KH: Oh my goodness, that sounds very nerve-wracking.

GF: No, it wasn't. (Laughter.)

KH: Well, at this point you had some different allies that you've mentioned helping you out within NIH, within Congress.

GF: Not within NIH.

KH: Okay. Within Congress.

GF: Yes, and most of them were the young people that worked for senators and congressmen. You know, it's kind of a fallacy that you go in and talk to senators, you don't, dear. You talk to their staff. I mean, they can't talk to everybody that walks into their office. They're busy people with lots of things going on. Every staff person has a different section that they're responsible for, for feeding back information to the congressman or the senator. So the thing is, if you have friends there, you will tell them and they will tell the congressman. But in saying that, we did get close to many, once we started lobbying and taking people around to meet them, people like Congressman Early from Massachusetts, Joe Early.¹⁵

¹⁵ Joseph D. Early served Massachusetts as a Representative from 1975-1993.

And we'd take pictures of the children we were going to testify with, we'd take the people around with us that were testifying with us, and take pictures and introduce them, so that they could see real people. And I remember so many times, you know, we'd bring back the children. And Rachel Dubin, who was, we had two children in particular. One had never had a cochlear implant and so did not speak well. Highly intelligent, went on to GW, and got, I don't know, master's, whatever it was. Then the other child, Caitlin Parton, was the first child in the United States, at two years of age, to get a cochlear implant. Two. So she spoke just like you and I are speaking. So I would take them around, and they came with their parents, we took their parents around. My mother came down, she met – well, that was another thing. We had just divine people to testify.

Marlee Matlin came, and first thing with Orrin Hatch, who was wonderful to us.¹⁶ And Tom Harkin wanted to meet her before she testified, so we went back in a little room, and she met them. Now this is a beautiful twenty-one-year-old girl. These men could hardly get one word out of their mouth to the next word, because they were so mesmerized by this beautiful young girl, which was exciting. I found that very exciting. And then after they spoke to her and they talked back and forth, then she went in to testify. I still hear from her interpreter, Jack Jason. He emails, and he's on all kinds of social things and the internet. We keep in touch with what's happening with Marlee. He was a wonderful person.

KH: So part of your campaign was reaching out to people who could come help you with outreach and testifying?

¹⁶ Orrin Grant Hatch served Utah as U.S. Senator from 1977 to 2019.

GF: Yes, and testify. And it goes back before, we really started off, Louise Fletcher.¹⁷

Fletcher was fabulous. We became good friends. She is a wonderful, wonderful woman. And her father was an itinerant preacher for the deaf. He and the mother both had a hearing loss, and one of them, I think it was the father, was holding onto a tree when lightning hit the tree, and he completely lost his hearing. And then he married a woman, Louise's mother, who had a hearing loss. So these beautiful children of theirs grew up having hearing-impaired children, and not only did Louise Fletcher come to Washington several times and testify for us, her sister Georgianna was there. She lived closer, in Virginia, and she would come and walk around with me. So it was a very wonderful time, and we had a whole spring of people.

There was Howard House, who had the House Ear Institute.¹⁸ He came to Washington one time; I told him he was going to come to a meeting that was going to decide whether we had a hearing institute or not. So he flew out, and he got off the plane, and I said, "Howard, I'm so sorry, but the meeting has been canceled. This is the bad news. But the good news is this." He flew out from California. I said, "The good news is that my secretary, Rosemary," beautiful Rosemary, who looked like a Botticelli, "we're going to take you to the best French restaurant in Washington." He ate lunch with us, just as if he had come from across the street, he got back on the plane, he went back to California. He was Ronald Reagan's personal doctor.

¹⁷ Estelle Louise Fletcher won an Academy Award for Best Actress in 1976.

¹⁸ Howard P. House, M.D.

KH: Wow, that's exciting. He comes back into the story later?

GF: No, that is the story of him. Somebody got it confused.

KH: Okay. So I wanted to ask a little bit more about I think then Congressman, formerly Senator Pepper's role in the creation of NIDCD.

GF: Oh, well, he's the first person I walked in to, because he knew my father, because he used to introduce my father as "my best friend, Harry Dietz." They had a wonderful relationship. He knew my mother. Did he know me? I was this big, nine or whatever. First of all, I didn't think I'd get an appointment, but I got an appointment, which I was shocked at. I walked in with an armful of pictures of my five children and my mother. This was really the only thing on my mind, to say hello to him, you know, "Remember me? Here's what I've been doing since I was a little girl." And so he listened all this, and he finally said to me, "Tell me why you're really here."

And I heard a voice in the room say, "Senator" – I called him Senator, even though he wasn't, I always called him Senator – "Senator, I want a separate hearing foundation. I want a separate foundation at NIH." And I don't know, it kind of petered out, and we finished our visit somehow, and he was on the phone on a speaker, because he wore two hearing aids. And so I said, "Well, I'd love to come back and see you sometime." And he said, "Let me know, call my office, make an appointment." And so I left. And that was it.

So I think I waited a little bit, then I called his office, and of course the secretary said, "What do you want to see him about?" I said, "Well, I had a meeting with him, and he said I could come and see him again, and I wanted to talk to him about getting a separate ear institute." That's the way I phrased it, separate ear institute. And she said, "Just a minute with that," and she left the phone. And I said, "Well, I'll never get an appointment now." She came back and she said, you know, she gave me a date and told me to come back, and I thought, "Wow."

So now I walked into his office on the appointed date. He was sitting at the desk. I walked in maybe from the left. Two people were standing on the right, Peter Reinecke, who was then his research assistant, and Kathy Gardner, who was his chief of staff. I walked in, and he turned to them; he said, "This is Mrs. Fox, she wants a separate ear institute, and if we can help her get it, we're going to get it for her." And with that, I'm in shock, and he dismisses everybody. And now I don't know, "Oh my heavens! Where do I start here? Who do I talk to, the man or the woman?"

I quickly ascertained that Kathy was the head, the chief of the staff, but somehow Peter was talking to me more and guiding me more. And it turned out that Kathy was pregnant, and she didn't really need another job, because she was busy handling all of the senator's things, plus being pregnant with her second child. So I kind of gravitated slowly but firmly to Peter, and there we were, and we start working. And he had another office, Bobby Silverman (phonetic) was also the staff director for Harkin, not in that

office but down below, a couple of floors down. So it's so many people that were there to assist me and say what to do at the next stage.

I remember saying to Bobby, one of the major hearing groups was against having a separate ear institute. Why, I don't know. But I said, "Bobby, what do I do?" He said, "Just ignore it, move along like you're moving along, and just forget about it. Whatever they say, just don't get riled up about it." So that's what I did.

KH: Wow. And so Peter Reinecke put you in touch with Tom Harkin's office, and that was how that worked?

GF: No, he was with Natcher. And then Natcher passed away after a while, but he was with Natcher, who was, and I have to get all of these things together here.

KH: I can always look that up.

GF: Well, he was the head of the, Natcher, he was the chair of the House Appropriations Subcommittee, Labor, Health and Human Services, and Education. And Silvio Conte was the ranking minority member. Now that was where we would go in, and it was really the first step. And after Natcher died, which was several years. I mean, Mike Stephens was fabulous; he was another fabulous one who worked for Natcher. Incredible. And I remember one wonderful story, which I have to tell you.

I would go in with my facts and my figures, sheets of them, and he would look at me, Mike Stephens, and say, “Gerry, I just want you to get a good hearing aid for my mother. That’s all. I don’t need your facts and figures.” And I realized he was absolutely right. But I had to have a talking point to continue what I was doing. So at the same time that Natcher and Silvio Conte¹⁹ being chair and ranking minority of this committee, Harkin had the same position on the other side. They had to have a Democrat and Republican. Natcher was chair of the House, and Harkin was chair of the Senate, of that committee, which was the Senate Appropriations Subcommittee, Labor, HHS, Education, and Related Agencies. Because that’s who we testified before.

I do have to mention that Tom Harkin and Arlen Specter worked so well together. It was a joy to see Democrats and Republicans working as well as they did. Never had a fuss, never had a word. And Natcher worked with John Porter.²⁰ He would be the minority. So it was Natcher, Silvio Conte was the ranking minority, but then Natcher and Porter worked together, too.

KH: All of these relationships and different –

GF: Yes. And all between Republicans and Democrats, and in the final hours of passing, that’s what they did. One Senate group had to pass something, and then when they passed it then the other group had to okay it.

¹⁹ Silvio O. Conte served Massachusetts as a U.S. Representative from 1959 to 1991.

²⁰ John E. Porter served Illinois as a U.S. Representative from 1980 to 2001.

KH: I have done a little bit of research on that, and it looks like from what I read that the new institute was very, very popular in the House. The bill for it had, from what I read, had 101 sponsors, and it was passed with only two opposing votes.

GF: Oh, that's good. That's good.

KH: That's what I read. So was this measure equally popular in the Senate?

GF: Well, I thought so, because it was Harkin. Harkin had a hearing-impaired brother, who worked for the post office, and hearing-impaired people could rarely get jobs, but post office was one place they could. In fact, one of the young men who testified for us was, well, there were three sports people, actually. One was an Olympic swimmer, one was a, they call it a short-kicker. He would do the kicking over the goal. And the other was Larry Brown, who was the NFL Player of the Year for the Redskins.

And if you want to see women come down out of the buildings like a rock star is there, that was for Larry Brown. We had women all over the testifying, seated to hear him.

And he was wonderful. The point of that story was, one of the people who was not Larry Brown, but one of the other fellows, his only job that he could get was for UPS, you see, because he didn't have to talk to anybody. So this is all sad things to hear, and if you have a chance to cure them and make them different, so that's it.

KH: So it sounds like part of the popularity of this work was the fact that so many people's lives were affected by hearing loss, and their families' lives, and that helped lead to support across the House and the Senate, across Democrats and Republicans.

GF: Yes. And you know, people, every time they're getting older, they might not have worn a hearing aid, I'm talking about Senate and Congress. But they might've known they needed one. Or they might've been at the stage where their mother and father had one. It was just making them aware.

KH: Were there any challenges to the legislation?

GF: If they were, we just disregarded them, and went ahead like Bobby Silverstein told us to do. Are you married?

KH: Yes.

GF: Okay, has your mother ever told you, "If your husband starts to argue with you, let it go in one ear and out the other"? She hasn't told you that yet?

KH: My mother has not said that, but I like that advice. (Laughter.)

GF: Yes. In other words, because what you're going to do is, you're doing to do what you want. You're going to do what's important to you. And even though somebody doesn't

think it is, they don't know you that well. You've had a whole life before he came along, right?

KH: I like that advice. I'm going to keep that in mind. That's the secret to campaigning in Congress.

GF: In a way, that was the secret, too. Don't get upset. We had the same thing happen eventually about when Reagan was signing the bill. We had one wonderful man, by the way, David Lim,²¹ because Bob Ruben came into the picture, and he was involved in the American Academy of Otolaryngology. So he and Joe Miller, fabulous, Joe was my go-to person, he was really for research.²² For questions, Joe was right there for me, like my best friend. He just passed away, David just passed away. It's hard, these brilliant people who were so helpful.

So Bob Ruben took care of the doctors, Joe Miller was a researcher and so was David Lim, and they handled that. I would write a letter to all the senators and congressmen telling them why I wanted them to support us, why we needed an institute. All you had to do was give this letter to all the heads of the department all over the country, let them copy it on their own professional stationery, and after you did that, we'd have everybody hearing from us. And so David Lim was fantastic this way. He would get everybody to be sure to send that letter back, be sure to put it on your professional stationery. So I

²¹ David J. Lim, M.D.

²² Joseph Miller, Ph.D.

would write the letters, and then they would pass them along and put them on their stationery. So he did that. He was fantastic.

Joe Miller, as I say, was my medical teacher. Any kind of a question, he would turn to me. And Bob Ruben, of course, was being sure that people knew the pros and cons of having your institute. Because people get scared. "Suppose we lose the funding we get from neurology. What's going to happen?" So he was there, and Dr. George Gates, were very, very wonderful people who arranged it so that they would get the pro and con meetings. They would get somebody that might even have been for the institute, but somebody had to take this role being against it, just to get the conversation started. So I had tremendous support from the doctors and researchers.

KH: And so, if I can just make sure I understand, they helped with helping you develop your understanding of the research so that you could go out and talk, they helped you reach out to the professional community and get letters into Congress, and then they rallied the advocacy through their professional groups.

GF: Yes, definitely. All of the above.

KH: And how did you meet, I know that you had met Dr. Ruben, for example, earlier.

GF: I can't remember how I met Bob. I do remember that when I was at Deafness Research Foundation, the woman who worked there, and I was sorry that they didn't pass the

directorship over to her. She was the secretary, but she was fabulous. She kept saying to me, “You don’t know Joe Miller, you haven’t met him yet. He’s the best researcher in the field.” So I kept hearing this name, Joe Miller, Joe Miller.

And finally I met him, and we just clicked. He was from Philadelphia, and his father was here, and he came back to it. But anyway, he married a lovely girl, and I was there for the baby being born and I got to hold this newborn baby. That was great. So it was a wonderful experience for me. I had fun. I was trying to reach a goal, but had fun doing it. I enjoyed it. I like people. So this was fun for me. That’s one thing; you do have to like people.

KH: Go saying hello to people you don’t know.

GF: Yeah. You have to be sensitive to them, too.

KH: You have to keep the good energy. I think I read that you had heard that President Reagan might veto the bill.

GF: Yes, David Lim told me that. But I said, “David, you’ve got to stop that. I don’t want any negative comments. I don’t work on negative comments.” So I said, “All right, but I’ll check.” So I asked my husband if he would call somebody, and he called, I’m sorry, I’m blanking on these names. This is terrible. Stop your machine while I think. We’ll just go back.

KH: So when you had heard President Reagan might veto the bill –

GF: Yes. I asked my husband if he would try to find out something, and he called Kenneth Duberstein,²³ and he asked Reagan, and Reagan said, “If there’s any bill that’s put on my desk, that’s one I’m going to sign.” And remember, I guess you have all these dates which were important, and I thought this was important because I didn’t really remember that on October 22, and it was in the final ten days of the 100th Congress that 238 bills were passed, one of which was the bill to create NIDCD. So that was just six days later; Reagan at his ranch, the California White House, signed the bill to create the Thirteenth Institute.

And that was done in two-and-a-half years, which was phenomenal, really. And we brought over the funding of \$94,947,000 from the institute, and that was appropriated. And Reagan signed the appropriation allocations for the new institute on September 20. So he kind of signed that before he signed the bill, it looks like. And on October 8, Senate passed the bill, Senate Bill 1727, to create a new institute. And then this was followed by the House, and then the full House passed it on October 13. That was for the Bill 1727. So that was it.

KH: That was a pretty big triumph. Did you celebrate?

²³ Kenneth M. Duberstein served as President Ronald Reagan’s Chief of Staff from 1988 to 1989.

GF: No, it was the saddest thing I ever felt. Peter and I had gone to the dome, and I was sitting way up in the rafters, and when they announced that it was – Peter was in another room down the hall, watching on television. And here they announced it, and I was by myself. I had nobody to share this with, nobody to pound on the back, or to hug or say, “Yippee,” or something. I was all by myself up in there, and it was so sad I could’ve cried. Then I left and I went out and found Peter and, you know, we were happy.

KH: It seems like a huge achievement to me, so that’s just very exciting.

GF: Well, everything you do in life to push things a little forward is a huge achievement.

KH: So now you had more work to do.

GF: Well, yes, because I thought that there were so many researchers out there who had wonderful ideas, but NIDCD can only fund so many. They have so much money, and they have to go through a process of how much money they have and who they can fund. So I decided to start my own foundation to fund young researchers who had an idea, and we would give them money to try out this idea, and if the idea worked, it could change the world, could change everything. But with this small bit of money, they would find out if it worked, and if it worked they would take that material and try to get it into NIDCD for more funding. So that’s really why I started the National Organization for Hearing Research (NOHR). And within the period I worked, we gave \$10 million away, within the period of I guess twenty-six years. So we did our bit.

KH: So you helped shaped new research. What stands out? Are there any areas that you feel particularly proud of?

GF: Well, I feel proud of all the research that's being done, because it's experimental and, again, if it works, it's beneficial to so many people. I was interested in regeneration of ear cells. That was my big thing. And yet, so many things have come along. Genetics have moved in there, and there are just so many areas that are important. People always say, "What has been accomplished the most?" Of course, it's cochlear implants, which is delightful.

It's wonderful, we now have children who were born deaf and can hear, and they can go to certain schools just for cochlear implant children. That was another person who funded me, George Nofer, who actually worked in the same law office my uncle did.²⁴ He was the head of this, it's schools all over the country, and it's only from infancy to, the goal is to get them into first grade at a school. What do you call it? Mainstream. That was the goal of these. And they take little tiny people with a cochlear implant. I have wonderful friends; my friends have changed, they're all young people now (laughter) with hearing-impaired children, which I love. But their children are going to regular schools now. Tough schools. They're not easy schools. They're going to well-known Philadelphia mainline boys' schools, things like that. And they're keeping up, and it's just fabulous. It's a wonderful thing.

²⁴ George H. Nofer.

KH: The field has really changed over the course of NOHR and NIDCD.

GF: Yes. Well, in what way do you think?

KH: I'm about to ask you that question. But I did want to backtrack a little bit to ask you about your time, I think you were on the advisory board for NIDCD after it was started. What were your duties? What did you do?

GF: I was the head of the board.

KH: What kinds of decisions?

GF: There were two. I was head of the medical board. They also had another board for probably researchers. Is that right? I think so.

KH: I think most NIH institutes have a board, particularly to award external grants.

GF: Right. And that was a funny thing, because it was a long, long table and no hearing equipment. So this is a hearing institute, but anyway.

KH: That's interesting.

GF: Yes it is. It was very interesting.

KH: Well, it seems like it would be a challenge to start a new institute. You know, you have your funding, but you have a lot to put into place.

GF: Well, by that time Jim Snow was head.²⁵ We had also Jay Moskowitz there, and he had vast experience, in NIH anyway. He was the Associate Director from 1986 to 1993.²⁶ So you had people that knew how the National Institutes of Health were run, and they were helpful. The first thing you did was go out and buy a book that told you what are the rules, that rulebook on how to conduct a meeting. What is the name of that? Everybody reads it.

KH: *Robert's Rules of Order?*

GF: Something similar. I forget. *Robin's Rules* [sic] or something or another. Anyway, all my friends who are now heading things, they go out and buy this book. We bring it home and study and we get the hang of it, you know.

KH: It's formal. It's a very formal way of running a meeting.

²⁵ James B. Snow, Jr., M.D.

²⁶ Jay Moskowitz, Ph.D.

GF: Yes. I always loved Ilsa Schwartz from Yale.²⁷ She would sit way at the end of the table. And she would go, “Dr. Snow, point of information.” She just wanted to clear something up, but that’s my favorite phrase: “point of information.”

KH: That’s a good one. So could I ask you a little bit about Dr. Moskowitz? I wanted to ask sort of what he was like.

GF: He was very nice, you know. They’re all wonderful. He probably went back into NIDCD, and also there was a gal who was in NIH. She was very helpful, because she knew the system. Coming in, it’s one thing to be on the Hill. There are no parameters there. You can really do your own thing, more or less, if you have a goal and you’re just working toward the goal. But now you’re in a situation that is formal, and you have to really work within that framework. So that’s what you do.

KH: That kind of has its own challenges.

GF: Yes, it does. That’s the beauty of life, of learning new things.

KH: I just want to go back a little bit to some of these early administrators and ask you if you remember anything about, you know, what they were doing. If you don’t, that’s fine; we can move on. When it comes to Dr. Snow, what was he like to work with?

²⁷ Ilsa R. Schwartz, Ph.D.

GF: Oh, he was wonderful. I knew him well from him being my own doctor at University of Pennsylvania, and he was probably head at University of Pennsylvania. He was very competent, just as Jay Moskowitz was, but Jay Moskowitz knew NIH. Jim Snow did not, so when I say he was competent, he was really a fast learner. He conducted a very fine meeting; always serious. He was a serious doctor. He studied, of course, under Dr. Bordley, and you couldn't get a better background than Dr. Bordley gave this young man.

KH: Is there anything you look back on during those years, I think Dr. Snow was Director from 1990 to 1997, and you think, "You know, that was a big victory for this young institute."

GF: To have him? Is that what you're saying?

KH: Or was there anything that in those early years under Dr. Moskowitz and then Dr. Snow that you think was a key turning point, or –

GF: Dr. Moskowitz was not there that long, well, wait. I shouldn't say that, '86 to '93.²⁸

KH: I think he was acting director briefly, and then Dr. Snow came right after that.²⁹

²⁸ Jay Moskowitz, Ph.D. was named Acting Director of NIDCD in 1988. He served NIH in many other capacities from 1969 to 1995, including a return to NIDCD as Deputy Director and Acting Director of Intramural Research in 1993.

²⁹ James B. Snow, Jr., M.D., was appointed the first Director of the NIDCD in February 1990.

GF: Yes, that's right. So Dr. Snow was the director as far as we all concerned. We all knew that Jay was only there temporarily. I seem to remember him going out of town someplace else after that. But Jim Snow was head as far as we were concerned, and Jay was acting, which we were all grateful for. We were very grateful. They were both very pleasant men. Of course, Jim knew research very well, and I would think that Jay was more into the nuts and bolts of an institute, so that he could help. Everybody has their strengths, so Jay had the strengths for me, and Jim Snow certainly did.

KH: And here's my last question about people you worked with at NIDCD. I wanted to ask about Dr. Battey. Maybe I'm pronouncing this incorrectly: Dr. Jim Battey?³⁰

GF: Oh, Jim Battey. Jim Battey came after Dr. Snow.

KH: Did you overlap at all with him, or is he later?

GF: A little bit, not much. I forget when he came in.

KH: I think he was Scientific Director in 1995, then Acting Director and Director in 1998.

GF: Yeah. Well, we did overlap, and of course he had an extremely fine background, and he related very well to the researchers.

³⁰ James F. Battey, Jr., M.D., Ph.D. served as Director of NIDCD from 1998 to 2018.

KH: So going forward over the nineties, you finished your work at NIDCD, and you focused more on your work for NOHR, and your funding for young researchers.

GF: Yes. Did we skip all that? Did we erase that, or no?

KH: I just stopped it while you were taking a drink of water, so I didn't record what you said about NOHR.

GF: But I think you got it before. We gave \$10 million to research. You heard that. We gave wonderful parties. What were they? They were teas for ladies. The ladies finally didn't have to ask their husbands for money to go someplace or didn't have to ask their husbands to come because they always wanted to stay home. So this way, it was in the afternoon. They could dress up, they could have hats on, gloves if they wanted, and it was a lot of fun. Everybody loved it. It wasn't that expensive to come, unless you were a sponsor. But to come, it wasn't that much money, and so everybody in town came.

The beautiful part of it was, it crossed the lines of religions. They had all kinds of religions, all kinds of races, creeds, and colors that would come. So this was, I felt, a good thing. And so everybody came. And we made a lot of money. And of course, it was all volunteers. Volunteers came to work at the teas. I paid nobody. I paid my secretaries, and that was it. So all the money that we made was free and clear for research.

KH: The hearing research had a broad appeal, as when you had been working on it in Congress.

GF: Oh, sure. That's when women came forward and said they were hearing-impaired. You can't tell with women with long hair. Or they wanted desperately to hear, and so now it was okay. "Well, if Gerry Fox says she can't hear and she's hearing-impaired, I guess it's all right for me to say it." So it opened a lot of doors, and it made it okay to be hearing-impaired, which was wonderful. Because then they could seek help, either medically or get a hearing aid, but to seek help. I guess I taught them how to get back into the world. You know, that's the way I felt about myself: "I'm getting back into the world." And I was very embarrassed. I didn't tell anybody, as I said before, that I was hearing impaired.

I remember Harris Wofford, who did become a senator.³¹ He was head of Bryn Mawr College. His wife was spectacular. She could have run the country. She could have been the Bryn Mawr president. She could have been senator with him, because she was Clare. She was fabulous. We went to lunch one day, and she said, "Gerry, why do you work so hard for this organization?" So I said, "Clare, I'm hearing-impaired." "You are? Well, I did not know that, Gerry." And I said, "Clare, you've never spoken so loudly or slowly to me. You don't have to do that now." But that was the reaction, you see, of most people who are with other people who are hearing-impaired. Now they shout at them, and it makes them feel worse, and the whole thing of just making us normal, of having people with a hearing impairment and we wear hearing aids and speak up.

³¹ Harris L. Wofford, Jr., represented Pennsylvania in the U.S. Senate from 1991 to 1995.

Then I got to say to people honestly, now I could be honest and I could say, “Excuse me, could you speak up louder? I’m hearing-impaired.” Or if I get to a dinner party, I’m deaf in my left ear, the first thing I do is I turn to the gentleman next to me, and say, “If you need me, I won’t hear you from this side, so just tap me on the shoulder and I’ll turn.” So I was very open about it and, in that openness, encouraged more people to be open and to get help. And that was kind of an aside from raising money for research, but everybody was interested in raising money to cure their hearing loss now. This was a good cause.

KH: You had a lot of different tracks of involvement in this issue.

GF: Yes.

KH: Just to walk back a tiny bit, what was your involvement with NIDCD over time? Did you decide to kind of step away? Did you stay involved?

GF: No, my term of office was finished. So the next person coming in was there, and now I moved on to NOHR, and from NOHR, not that I’m involved in Hopkins, but one of the young women who very early in the game won the Young Investigator Award, Elisabeth Glowatzki, is now conducting research for me, kind of in my name, but it’s not, it’s in Hopkins’ name for NOHR, under my involvement with them.³² And also, she is running the Young Investigator Award. I just heard from her. She is an incredible, incredible researcher, has always been. She’s from Germany.

³² Elisabeth B. Glowatzki, Ph.D.

She was just given a grant before NIDCD. She got the highest, 3 percent top of all the institutes of acceptance. She got a five-year grant. She's a spectacular woman, a spectacular artist too, like her mother. Don't you find that the talented people are multi-talented? So she is one of those, and she just runs a wonderful research lab. With a little bit of money that she's getting from me, she is able to bring over people for the lab and get them started. And also, she's still giving out the Young Investigator Award, and now she is taking more people than just the board. She's taking people from multiple boards.

KH: Are there any areas of her research or her laboratory that you wanted to mention?

GF: Well, she just got this five-year grant, so I'm going to let that come out first. I don't know if they're releasing that information yet, but that is really, I think, something that you could look up. But she's really wonderful. But I think a more interesting story is Dr. Fuchs, who is head also in the same department. He told me that he was in another field than hearing research and he couldn't get a grant, but we had grant proposals out there, so he decided while he was waiting, he would try to get a grant proposal. It turned out he got one of our grant proposals, and it hooked him. He became so fascinated with hearing research that he switched careers. Ours was his first grant, and now he's head down there in one of the departments of otolaryngology. Paul Fuchs is his name, Dr. Paul Fuchs.³³ He and Elisabeth work in the same department.

KH: So this institutional support is growing the field. Growing innovation.

³³ Paul Fuchs, Ph.D.

GF: Yes it is. And all these young people who are Young Investigator awardees, they're way up top now. They're the ones that are leading the field now. And they are; they're all leading the field. They're great.

KH: I wanted to ask a little bit about looking ahead to the future. What do you see in the future of NIDCD? Do you see anything in its future? Any challenges, any coming accomplishments?

GF: I hope it lives a long, happy life. I hope it has good lobbyists going before Congress and asking for money and telling them what they have done with their money. "This is what we did with your money, and we accomplished this, A, B, C. We have accomplished this. But as much as you have given us and how generous you have been, we need more to continue the fight." We always need more. Research takes a long time. I go to the Albert and Mary Lasker Awards every year in New York. They recognize worldwide researchers; for instance, hepatitis. They've cured hepatitis; they were just awarded. Some people get up there, and they get an award. They've been working for thirty years on something. It's not quick. It's not a, "Give me your money and I will get an answer." Research takes a long time, and I hope that we can teach people, "Never stop funding the research that means a lot to you, because this eventually will get the right answers."

KH: Do you have advice for a young person who's interested in impacting the lives of those affected by hearing loss or communication disorders?

GF: Oh, absolutely. We need more people like you. We need more people like you to, as I always say, get comfortable shoes and walk around the marble halls of Congress, because we need people spreading the word. When I retired, I really wanted somebody like me to head my foundation. I wanted somebody who was passionate, which, that's me. That's about the word to describe me. I was passionate about this. Unfortunately, you had to be more than passionate. You had to have the time. You had to have the money to do things when other people wouldn't help you. So it was a couple of things that had to happen, and I wasn't able to find that person.

And if you look around, the people that start things like the Diabetes Foundation, Lee Ducat, wonderful friend of mine. I always said, "If there were a cure for diabetes, it would be for this young mother, whose son had diabetes." You can almost check every single disability and find that there's probably a young woman in the back of it. I'm sorry to say that, but I know several instances where there are women whose children had it. They had something. They start a foundation.

Cystic fibrosis, same thing. I know them here from Philadelphia. Their child had cystic fibrosis; they started a foundation. These aren't small. I mean, you still know the word Cystic Fibrosis Foundation, Juvenile Diabetes Foundation. They're all started by women. Unfortunately, it takes that passion, that desire, and all we want to do is move things ahead a bit. Just move everything a step ahead, because eventually it will all happen. Do you get disappointed? Yes, we get disappointed there are no cures. Okay? But

eventually there will be one. It definitely won't be in my lifetime. It definitely won't be here. But maybe my children's lifetime. And that's what's important, that we all keep moving the field ahead a little bit. Just a little bit; just don't stop.

KH: And in terms of cures, possible and future, do we need more people to participate in clinical trials?

GF: You have to have the research. When you get to that point, yes. Okay, I'll put it that way: When you get to that point that you're ready, yes.

KH: Were you ever interested in participating in a clinical trial?

GF: I was never asked. I mean, for what reason? Research was not ahead to do that. The research wasn't there.

KH: Okay, thank you so much. Here's my last question. Is there anything I haven't asked that you wanted to mention or you'd like to talk about?

GF: No, I think if you were just recording what I said before about getting more people involved and working for the cause that they believe in, you know, whatever it is, I think that that's the important thing. Research is prime. Research takes money. There's no getting around it. And if you're passionate about curing something for a loved one or for

yourself, then you've got to get involved. You can't just wait for somebody else to do it.

That's all.

KH: That makes sense. Thank you so much.

GF: You're quite welcome.

[End of interview]