

**National Institute on Deafness and Other Communication Disorders (NIDCD)**  
**National Institutes of Health**  
**Interview with Dr. Robert J. Ruben**  
**Conducted on November 2, 2018 by Kate Hallgren**

**KH:** This is Kate Hallgren, Senior Historian at History Associates. Today is November 2, 2018. Today I'm honored to be interviewing Doctor Robert J. Ruben, Distinguished University Professor at the Department of Otorhinolaryngology-Head and Neck Surgery, as well as Professor of Pediatrics, at the Albert Einstein College of Medicine, Montefiore Medical Center. He was also a key historical actor in efforts to found the National Institute on Deafness and Other Communication Disorders at the National Institutes of Health in the late 1980s. I'm happy to be speaking to you today. I wanted to start by just saying that I understand you grew up in New York City?

**RR:** No, I was born in New York City, but about six months my parents moved to Great Neck, which is a suburb.

**KH:** And what was that like?

**RR:** Back in the thirties, it was pretty rural. We would catch striped bass in the bay, and flounders and eels and things like that. Then the war came, and right after the war at the Sperry Gyroscope Plant, which was Manhattan Project, the UN met. So during my last few years of high school, I had the real privilege of growing up with a lot of kids my age who came from all over the world. So it was a rather fascinating cultural experience.

**KH:** Wow, that sounds pretty incredible. Were you interested in science when you were at school?

**RR:** Yeah, I always was—my earliest memories with erector sets. My parents sent me to camp at age five, which I detested. I'd much rather dissect frogs and look at how flowers went. I was also always somewhat active politically. In high school I was president of what we called the Agassiz Club, the biology club. And I had a whole chemistry lab. We had a porch off of my bedroom, which was enclosed in glass, no heat. So I had to have a heater there in the winter time, and I had a whole chemistry set. Once I blew all the windows out. I still have a scar from that. I even made rocket cars and things like that.

Somewhere about my sophomore or junior year, Bar Harbor burnt down. Bar Harbor, which was the genetics mouse lab, sent out an appeal to high school students to trap mice and breed them, with the hope that they could get some species. So at that time there were about forty acres of essentially prime forest behind the house where we lived. It's now all developed; it's gone down the drain. So I quickly, you know, followed their things.

You got a coffee can and a mousetrap, where the mousetrap would go like that, and it was a screen, so you can trap the mice. And I ran a trap line and trapped a lot of mice, and I knew a little bit about genetics. We had a wonderful biology teacher, Mr. George Nuys (phonetic), and he kind of tolerated me. And I then inbred them, and

back-bred them, and as I was cleaning their cages, I had this kind of metal thing that I put them in, because I had to make sure the males didn't get in with the wrong females, so forth and so on.

And I noticed this, as they were running around because it was noisy, they'd all of a sudden have what looked like a seizure. So that's interesting, so lo and behold, what did I do is essentially got a purebred of those with the seizures; it's a recessive. That became audiogenic seizures; it's still there. And I got an honorable mention in Westinghouse,<sup>1</sup> which was quite something for high school.

Also, my father's physician was a man by the name of George Katz, who was among so many German refugees. He was from the Charité of Berlin,<sup>2</sup> and he was one of the guys who developed sedimentation rates. So he came to Great Neck, and my father must have known him through family. And he had his own practice, and he was very German, but taught me. In fact, he had a huge skeleton; I don't know where he got it. He gave that to me. I gave that to the high school. So I was in this from the very beginning.

Then as we had a conversation before, I finally got tired of camp, didn't want to go. Saw an ad in *Natural History* magazine, which I read avidly, to a thing called prairie trek expedition. So off I was, put on a plane, and landed in St. Louis. Doc Olmstead threw me in the back of a pickup, and for the next two-and-a-half or two months we went

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<sup>1</sup> The Westinghouse Science Talent Search.

<sup>2</sup> The Charité Universitätsmedizin Berlin.

around and I collected parasites of reptiles, including rattlesnakes, pressed flowers, hiked through New Mexico to Inscription Rock and back, and things like that.

There I also learned about dendrochronology, how to date things with trees, which gave me an interest in archaeology. I almost became an archaeologist. So that was kind of a lot of fun. So then I continued in the science, and also after that I worked at Settlement House camps for two summers, because curious how the rest of the world functioned.

Obviously got into Princeton, which had a Jewish quota those days. That didn't bother me, I just got an education. At Princeton, at that time I was mainly interested in intelligence and things like that, so I decided to become a psychology major. Well, it wasn't very popular, and my advisor was a guy by the name of Ernest Glen Wever. The first thing he did, not to assign me in what I was interested in, was physiological optics. Now little did I know that Glen Wever was probably one of the two or three most important ear physiologists in the world at the time, but he was a very humble man. I did that, got hooked.

Remember, Walton,<sup>3</sup> who just won a Nobel Prize, came to Princeton to talk. I was probably a sophomore or junior, and we all had our white bucks and khaki pants and button-down collars. I was upstairs and they were sitting in amphitheater; I think it was probably in the chemistry hall. And Walton was just about to begin, but the first seat left was like, in prances Einstein, poor Nobel laureate just stands speechless. Einstein comes in, takes off his cap. The hair goes up, the hair goes down, and Walton talks.

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<sup>3</sup> Ernest T. S. Walton, 1951 Nobel laureate in Physics.

So I got really fascinated in this, and by this time I did probably the first paper. I looked at comparative IQ studies in reform school children. All of them if you used the standards of the day were retarded, but obviously working with these kids somewhat, so I also used Raven's Progressive Matrices and was able to show the difference. But by this time I was really hooked on physiological psychology, and decided I would like to spend the summer.

So I wrote to Keffer Hartline at the Jenkins Lab in Hopkins. This is about two or three years before he won a Nobel Prize. He didn't answer me. I was indignant, so I wrote another letter and finally Ted MacNichol,<sup>4</sup> who we became very good friends, decided that I can come. I assume my salary came out of his pocket, twenty bucks a week. I started out first as a tool and die maker for them, and then I was running the experiments with the *Limulus* that got Hartline, for good reason, the Nobel Prize.

One of the great secrets which we can tell now that Keffer didn't want out is that he was working on an Office of Naval contract. To keep the *Limuli* alive, he needed seawater, and the Navy was buying seawater, refrigerated, at ten dollars a gallon. So that got me started on that, and finally, I did my senior thesis at Princeton. MacNichol had worked up at the radar lab at MIT during World War Two, and from Ted I learned a lot about amplifiers, which they needed for low signals.

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<sup>4</sup> Edward F. MacNichol, Jr.

This is before the day of transistors, so for my senior thesis Princeton I modified Ted's amplifier a little bit, and I redid Lord Adrian's work, and was able to show single active fiber. I think it's one of the shortest senior theses in Princeton; it's only a page-and-a-half, with two illustrations, which I got what today would be an A+. Then I wound up at Hopkins, probably for all the wrong reasons. (Laughter) I wanted to study biology, and that's another long story.

**KH:** Okay. Well, I'm interested in that story. That was sort of my next question. So you were still in psychology at Princeton, but you were interested in biology. You had been performing experiments over the summers, your thesis had to do –

**RR:** Also, I was Wever's technician. I learned my operating skills in two places, one being Wever's technician, how to use a microscope, which wasn't used in surgery those days but he did it, because we were tying strings around the middle ear muscles of cats. Which was interesting. The other was kind of extracurricular. One of the things that drove me to Princeton was the polo team. When I got there, no more polo team because the horses were smuggling in dope.

So the next thing I thought I'd do, because I had boxing lessons as a kid, I'd go on the boxing team. Luckily, they stopped college boxing about a month or two in it, because too many kids were getting killed. The man who taught boxing was a wonderful guy by the name of Joe Brown, who had been a boxer, was Jewish, one of the few on faculty. Didn't see in one eye, but was a great sculptor, and if you go down to the Dillon Gym

you'll see these things. So at eighteen years old, I did live sculpture from a nude model, and that probably taught me more about surgery, how to look at things in three dimensions, than anything else. So this was other things that were going on at Princeton.

Then I, you know, had three choices at the end, either to go to MIT for PhD, or go to this new thing called Rockefeller University. For X, Y, Z reasons, this didn't appeal to me. I was interviewed at Harvard for medical school, and they sent me straight over to MIT. (Laughter.) I had some funny adventures. Then Bard,<sup>5</sup> who was the dean at Hopkins, kind of understood where I was and fine, and the other chap who interviewed me, I said, "Oh, this is the end."

But it seems that his grandfather had translated the Sioux Indian language into a Bible, and the summer between my freshman and sophomore years I became a migrant laborer cutting wheat, and then when the wheat ran out in Kansas, I went up to Midland, South Dakota, and became foreman of an REA. We did electrical poles, and the reason I was foreman was I could read and write English. My crew was all Sioux Indians, and they taught me how to climb poles, use dynamite, so forth and so on. I got one of them to a hospital. Then with the money that was left over, I bought an old car, sold that, bought a horse and pack-horse and took it down from Rapid City to Denver and took the bus home.

**KH:** Wow, you really made a lot of use of your summers.

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<sup>5</sup> Archibald Philip Bard, Ph.D.

**RR:** Oh, yeah. Then the next summer, one of the great courses I had at Princeton was Thorp's American Literature. We had read *The Education of Henry Adams*, and chapter twelve was called "The Virgin and the Dynamo." Here his friend encompasses the—this is written about 1912—machine age by holding the motorcycle, and he goes to Burma Pass and dies. Well, I thought this was a good idea. I had made a lot of money cutting wheat, in fact, it's probably supported me for most of my life in one way or another. So off we go with a student ship (inaudible 00:12:32). Rotterdam, I'm met at the docks by the (inaudible 00:12:37) because I'm the first in my family to turn out not be a banker. And bought this BMW with a crankshaft instead of a chain, had never been on a motorcycle. Took it three times around the court, and off I went for two-and-a-half months. Then my other part of life, finally, you had to come home eventually. (Laughter.)

So I sell the motorcycle in Amsterdam, and I go to another not-so-distant cousin (inaudible 00:13:06) Israel and bought my first antiquarian medical books, which, one of the rooms here in the apartment is about a thousand of them. Also bought my first artist's book, which I don't know. But first I'd bought a present for my mother, my father, and my sister. Then with the leftover money, which was considerable, bought the books, hitchhiked back to Rotterdam, the young ladies bought me beer all the way home. So those are just some of the adventures.

**KH:** What was it like when you started medical school at Johns Hopkins?

**RR:** Interesting. Number one, we had two quotas at Hopkins in those days. Thanks to Mrs. Garrett, 10 percent women, and, thanks to prejudice, 5 percent Jews. That never bothered me particularly. I was really interested in doing neurophysiology. I mean, boy that was great. During my physiology class, Vernon Mountcastle, who later we sat on NIH committees, was trying to do a demonstration. He couldn't get the cathode ray oscilloscope working. I volunteered, "I can fix that, Professor Mountcastle," came down, had no realization of the animosity and jealousy this man had. I did it, and one look from him, I realized I could never get near neurophysiology at Hopkins again.

So I then decided electron microscopy looked interesting. That guy wasn't interested in medical students. I thought I'd do otolaryngology, and meet Stacey Guild, and I can give you a copy of a monograph I wrote. He was locked in a broom closet, because the chair before him wasn't happy, because Stacey showed up what he was doing was wrong. I've written about that and published. So that was no good. So finally I wound up in neurosurgery with Earl Walker, and some of my first publications in *Journal of Neurophysiology* was looking at temporal lobe epilepsy and how that went through. I built a machine to measure Parkinsonian rigidity, and I was just happy as a clam. I was going to go into neurosurgery.

Then one day, I get a call from John Bordley, he's chairman of the division of laryngology and otology.<sup>6</sup> I didn't know him from a hole in the wall. I walk into his office, "I'm a third-year medical student." "Well, Mr. Ruben, we have an NIH grant and our principal investigator has decided not to come. From what we can determine, you're

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<sup>6</sup> John E. Bordley, M.D.

one of the only person in the whole Hopkins community who knows anything about the physiology of the ear,” from my work with Wever. “We would like you to become PI.” Okay, I sleep on this. (Laughter.)

There was some unpleasantness. I had been invited to a dinner party, part of the people of the Cone Collection, Gertrude Stein’s family. Not who I am, but who my folks were. And I’m really bubbly about this, and I’m going on my whole picture of the house, Giacomettis and the reflecting pool, Picassos on the wall. He says, “Ruben, you’re not to take that job.” Why? No Jew had risen above the rank of associate professor at Hopkins, with one exception, Arnie Rich who converted to be an Episcopalian. So I went back home and thought for a minute or two, and took the job, and I was never invited back again. (Laughter.)

So this became very interesting experience. I’m a fourth-year medical student and a house officer running a lab. I’m getting fellows, a bunch of them are dead, from all over the world, many of whom became full professors and departmental chairs while I was still a third-year resident. This became pretty odd socially. By this time Stacey Guild, and I’ll give you a copy of the monogram, was out of the broom closet. Bordley was a good egg, I mean really good. We got to be very friendly later on in life, especially before he died. I got to know Stacey very well. I’ve never really been mentored, and I mentor people now, but Stacey gave me some good advice, like, “When you write science, pretend you’re writing for the daily news.”

So I ask Stacey, “Okay, everybody can record these cochlear potentials. Hell, I’ve done it off of snakes, lizards, fish, turtles, you name it. Why hasn’t this been done in man?”

Stacey says, “Can’t be done.” “What? No?” “Wever and Békésy, this is before Békésy got a Nobel Prize, and Meltzer,<sup>7</sup> up at Lempert’s lab,<sup>8</sup> a thing here in New York, tried and couldn’t. The Russians, maybe, maybe not.” It doesn’t make any sense to me.

So, remember how I built the little amplifier? I built another amplifier, and I borrowed the cathode ray oscilloscope, which was on wheels because I already had a lab, but couldn’t move mine, from Mackenbach (phonetic) and Kannhoven (phonetic), the people who did all the heart work, they were good friends, and went to the operating room, and Al Liberman (phonetic), who was the otologist, very nice sweet guy, was doing a stape. He’s like, I couldn’t operate and put my electrode there, and my amplifier was right here, and the rest is history.

So then, by this time, I said, “What the hell went wrong in New York? Why couldn’t they do it?” So it was pretty bad even in those days. Bordley said, “Okay, why don’t you go up to New York, and please tell Dr. Lempert he’s getting the gold medal.” Okay, we’re going up to New York. I’m to tell Lempert he got a gold medal. There’s a whole story about Lempert, why he wasn’t in the American Otological, needless to say, I was well-received.

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<sup>7</sup> Philip E. Meltzer, M.D.

<sup>8</sup> Lempert Institute of Endaural Surgery, founded by Julius Lempert.

And Liber (phonetic) was in the hospital with a kidney infection, but Békésy was there, and he hadn't gotten his Nobel by that time.<sup>9</sup> But it took me less than a nanosecond to see the problem. Lempert had spent a lot of money building an electrically-shielded operating room, and they put Wever, who wasn't there, and Békésy in a recording room about fifteen yards apart. They ran the wire all the way there, and the amplifier was too far away, so the signal was lost.

So there, Békésy gave me two very good, he and I get along quite well, because his major interest outside of science was pre-Columbian sculptures, and one of my very good friends, also now deceased, is one of the principal collectors of this, so I wasn't entirely ignorant. Békésy said two things. "When you do a paper, put it in the drawer for six months and then take it out." I followed that advice. "Number two, in science, enemies are much better than friends, because they'll soon find out where you're wrong, and as a good scientist you should always hope you're wrong and will be disproved the next morning." He was a delightful Hungarian. So that's what we did there.

Then in the lab, we did a lot of things. I started to really get interested in deafness, did a lot of work on genetic mice, here I am, back to where I was there. Also was looking at the (inaudible 00:20:47). I remember one of the things that, because my only publication, the Institute of Electrical Engineers, was I built a machine that could tell you what was happening before it happened. (Laughter.) Again, we didn't use transistors or bits in that days.

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<sup>9</sup> Georg von Békésy, Ph.D.

It was simple-minded. We have chronically-implanted electrodes in a cat, and we had a tape loop that went around and around, so we know that with the conditioning, we knew what happened a hundred milliseconds. We could take that off the tape loop and record it, and what we were looking at was how much of an inner ear did you need to make a phony discrimination between “cat” and “bat”? The “ats” were exactly the same. So we’re doing stuff like that. And then genetics, and working this out.

Meanwhile, I’m being a resident and learning how to take out people’s larynxes and so forth and so on. But also, the cochlear recordings were the first really objective, reliable way of determining whether an infant was deaf or not, so we were testing lots of kids. I was taking informed consent before it was even popular. Then I’m working with the mice, and finally I said, “Okay, it’s interesting to look at physiology, but the only thing physiology is going to tell you, it doesn’t work, it doesn’t work.” It’s not gonna let you there. Also because I was looking at temporal bone slides, also because we had such a good temporal bone lab, I was able to process the temporal bones of our deaf mice and find out most of them, when they were physiologically deaf and behaviorally deaf, still had all the bits and pieces in there.

We didn’t have electron microscopy at that lab at that time, but that struck me. Then I knew things from rubella. Without going into everything, what struck me was that a lot of congenital deafness, and even deafness later on, was due to premature cell death. So let’s find out how the ear was put together in the first place. So I’m down at NIH as the first ear, nose, and throat doctor to be a research associate. I’m in, first, Columby’s

(phonetic) lab, which was the eye institute, because there was no ear, nose, and throat.

Here I did probably the most lasting piece of scientific work, I did the terminal mitosis of all the various cells within the inner ear. That's still referenced now, almost a half a century later.

**KH:** Because it helps people identify how the cells of the ear affect –

**RR:** Yeah, we know the time things, and they can start to intervene. The other thing too is I did that, I keep on doing things that people say can't be done. (Laughter.) Then it struck me, "Okay, now we know the basic building block, how to start from somewhere." I was well aware of that in salamanders, newts that the ear can reproduce. I was also well aware from Jeff Corwin's work that sharks just grew more cells. And it struck me that the way to really understand and perhaps intervene in what's going in the inner ear was to be able to take this out of the animal, so we can control it. That's called organ culture.

Again, "Bob, people have tried. It can't be done." So I found a technician, Tom Van De Water, who knew about tissue culture, which, I knew nothing. NYU for two years, which was relatively unpleasant. We built a lab, and we did the first organ culture of the mammalian organ of Corti, and every laboratory in the world's using it. So that's become another tool.

**KH:** I'm so fascinated by the way you went from the physiology to the cellular, even DNA-level, to tissue culture.

**RR:** Oh yeah, I did the early work which I published on RNA, looking up the problems like that using the organ culture. Then I wound up at Einstein, and how I wound up there is that Doctor Isabelle Rapin, probably the foremost pediatric neurologist, she just died about a year ago, had been working with low-potentials, not getting very far, and she knew what I had done. I had corresponded with her while I was still at Hopkins. She met with me here in New York, and she was interested, and she had tried to do some animal work and showed me some slides. I was still at NYU, and I said, “Isabelle, tsk, tsk, those are all artifacts.” So she dumped it in the wastepaper basket, and we became very fast friends.

I was ready to leave NYU for a number of good reasons. My father had died when I first got there, so I had to hang around for a certain amount of time to take care of the bits and pieces. So Isabelle decided I should come to Einstein. Well, she gave her one and only dinner party. The dean at that time was Harry Gordon. Harry Gordon was also a Baltimore refugee like myself. He had been head of pediatrics at the Sinai Hospital. He’s the man who did all the work for the Kennedy Centers, because of retardation. Guess what? He was only an associate professor there. But by this time he’s now dean at Einstein. So they recruited me to Einstein as an associate professor and head of a division. I’ll give you the book of what happened here. I then quickly became a chair, head of a department.

And then when we moved up there, Tom Van De Water by this time had become a graduate student. They didn't give me very much, but it was a Faustian bargain. In those days, otolaryngologists with an NIH grant, that was a total anomaly. So to have the freedom to what I wanted to do, I said I'd take the administrative burden. You'll see that got a little bit too much after twenty years, after twenty-five years. I did it for thirty years.

And so we went to the old Van Etten TB hospital, and they gave us all the space we wanted. It was empty, so we took an old pantry, and worked a weekend and built that into a room where we can build organ cultures, so forth and so on. And we did all that. Then what also happened there was, because I was head of ENT, they thought I knew something about deafness and speech and things like that, and CERS, the center for retarded children and things like that, had a communications disorder group, and they made me head of it. I didn't know anything about it, but I kept notes.

After about six months or a year, it finally went through my thick head that the major problem was not hearing. Those were easy. It was language. And this then brought me back to what I'd done at Princeton with IQ, and went down the merry road, and I think if one of my, probably two or three of what I consider my best clinical contributions was now bringing language as fundamental yardstick for both evaluation of a patient and a outcome measure.

That's another funny story. At the first pediatric conference held in Nottingham, they asked me to keynote it. So I keynoted it. By this time, I had also headed up the FDA thing on cochlear implants in children, and they had set their criteria before anybody had thought of language, so it was just detection: "Does this sound like that?" so forth and so on. I said language had to be the outcome measure, and I thought they'd take me at the crossroads and put a stake through my heart and bury me. (Laughter.) I was very, very unpopular for this.

**KH:** With your peers?

**RR:** Yes. That's happened to me a couple of times.

**KH:** Why?

**RR:** Because they didn't like it. They were very happy with just using speech. They didn't like somebody telling you, "That's useless; what you really want to look at as your outcome measure is, what is the linguistic ability of this child? Is this good as sign, better, or for worse?" I mean, why did Sutton rob banks? Because that's where the money is! Okay, so two years later, my friend, who was Professor Leow (phonetic), had a conference on language as the outcome measure, which I keynoted and so forth and so on. So that's come about, now everybody uses that.

**KH:** Was that a little bit cross-disciplinary to use those measurements to develop adequate tests?

**RR:** Yes. I published a number of things of how you can use this in making a decision. The other thing, which I got into long before I even knew what I was doing, like most of the things I do, is this whole idea of precision medicine. About twenty-five, thirty years ago I'm doing a paper on otitis media. Looking at that, I was really interested in inner year, but all my friends were in otitis media. So, "Hey, Bob, just do something." So it struck me, the very fundamental question, "Why does Johnny get sick and Amy doesn't?"

Three things. One, intrinsic susceptibility, what genes did you get? What's that? The second, extrinsic susceptibility, whether it is poor language input, you live above the Brooklyn Boulevard, get all the fumes, so forth and so on. Thirdly, it's the strength of the vector causing the disease. A forty-five to the head is a pretty strong vector, no chance, a little bad bacteria. So these three things, I shouted about those as well.

The other thing too, which struck me is we have a lot of kids with tracheotomy living in the hospital for two or three years. The mortality from that is pretty high. Actually, I didn't do it for mortality. What I did it for essentially was that these kids were isolated. Even though the nurses were being as nice as they could, they weren't getting cultural, linguistic input.

So in the Bronx, with single moms, we did this, you know, craps with snake eyes. We ran a study for about a year or two where we sent the kids home with all types of protection. We published the study, we had reduced the mortality by a factor of ten. And this has now become standard operating procedure. So the language, there were a couple of other things that I did as well. But all this came out of work, working in the CERS clinic. I really realized about language.

Probably one of the best things that happened there is we published a paper, that's before I had any sophistication in language, but used a rather crude measure of looking what the effect was of giving hearing aids with children with less than profound hearing loss who were diagnosed late. They were usually considered dumb, retarded, blah, blah, blah, and we looked at their language scores before they got the hearing aid at five or six, and looked at their language scores four or five years later. Guess what? No improvement. That's essentially the critical period.

Then that got us ahead of the most wonderful developmental officer Peter Leyden (phonetic). Montefiore made a mistake in getting rid of him, but that's their problem. We had a lot of patients gave us money, so forth and so on, so Peter said, "Let's have an evening where we're not going to ask for a penny. We're just going to do a dog and pony show, what we're doing with their money." So we did it here over at the Union Club, and part of our pony show was Judith Gravel, also now deceased, who was the spearhead for newborn infant screening, pilot study we did here in New York, and I'd played a role in that as well.

We're talking about the late diagnosis of less than profound hearing loss, and one of my friends asked if he could bring a guest. My mother was very smart; she said, "Bob, whenever you give a party, the only ones who are unhappy are the ones you don't invite." So I said, "Yeah, bring them." It seems that this guest had a niece same way, and had really resonated, and she wrote a check that evening to build an extra floor to our children's hospital.

So I'm down at Hopkins last week, and they're showing off their new children's hospital, built three years ago. Ours was opened in the year 2001; they copied what we did, but not as well. I had a lot of input in this hospital. Each floor is aimed at the age of the child, so that the child and the family has an educational experience, besides whatever we do to make them the better.

**KH:** That sounds amazing. I just want to walk back a little bit –

**RR:** Is this going where you wanted?

**KH:** This is fantastic. And you know, I may ask you a few details and –

**RR:** Sure. And I've got some stuff here I want to talk about too.

**KH:** So you've sort of talked about this but I wanted to ask you explicitly, even back when you were a medical student and a resident, balancing your work with patients, your clinical work, with some of your research, whether that work informed how that work sort of, did it or did it not intersect for you?

**RR:** I'm good at multi-tasking. (Laughter.) That's the only way I can answer it. No, I would do tonsils, I'd take night call, I'd be in the ER. I had fellows, I would go up there, I would work with them at odd hours, and you just made it all work. I wound up with a huge operative list, I knew what I was doing as a chief resident, I did the administration. I think one of the great memories I have is, you know, I almost did neurosurgery.

So at the end of residency, Dick Otenasek, who was the chief resident in our surgery, and I were chatting, coffee in one of the hospitals. And I was saying, "Dick, you know, this ENT is so great. Our patients say, 'I look better, I can hear better, I can smell better, I can talk better. My voice is better.'" And Dick let me go on and on. He said, "Neurosurgery, we're just happy if they can say, 'Gee.'" (Laughter.)

**KH:** You also mentioned informed consent, and how you were using that early on. How did that come about?

**RR:** Yes. My moral upbringing. You don't do experimental things that, again, I've written about this later on, especially informed consent in surgical procedures, what you do with children. It's just the way I was brought up. Which I found out later, I've done a lot of

work in history of medicine too. This comes from Hopkins and Owsei Temkin. I did, you know, maybe twenty years ago, time goes by, had a conference here through New York Academy of Sciences on the genetics of deafness.

I'm not a geneticist, but I wrote the history of deafness and genetic deafness, and I stumbled across Oscar Wilde's daddy, Sir William Robert Wilde. And he does many, many things, including the census of the deaf, where he asked for informed consent, but this was long after. Well, I wrote about that, and that was interesting. I had known his great-grandson, Merlin Holland through one of the clubs I belong to here in town. I thought, "Gee, I've had drinks and eaten with this guy; I ought to show him the paper about his great-grandfather, and make sure I didn't mess up." I got back an email. I have it here. This is the first time he thought he's changed his name back to Wilde.

Then just a few weeks ago, I was in Dublin with a study section in history of medicine, which I put together with two friends, one from Lucerne, the other from Ulm. So in Dublin, I decided to do another Sir William Wilde, but now all the things he did that were not in medicine and science, which includes travelogues, histories, folks' things, and some of his works as travelogues are still in press. He wrote whole museum catalogs; good fun, that's all those books from there.

**KH:** Okay. And you also mentioned working on infant screening in New York, and I think you said that was a pilot program.

**RR:** Yeah. Given my orientation that the earlier you get something into a kid's head, the better off you are, I was part of a number of NIH conferences before we had the tools to do this. I remember one of them, we were discussing, it was a lot of things I'm addressing, so I have the bright idea that one of the things we could do is that every box of Pampers, every box of formula should have the following statement: "The Surgeon General says that if you don't have two words by one year of life, your child may have a communication disorder," so forth and so on. The Surgeon General was in the audience. She really got angry at me. (Laughter.)

But anyway, this was really, really important, so Judy Gravel, who joined me through many years, really took hold of this. They then organized, and they did the first whole-state screening. The first screening was done by White out in Nevada, and he did that in Providence, but it wasn't a whole state. So Judy and other colleagues did it here, which we backed and so forth and so on, and this finally led to the establishment of now national newborn, and I have a whole paper of it and about that, and we're now screening about 98 percent of the kids, which is making a real difference. However, we were missing a lot, and we were certainly missing a diagnosis on children who would have later onset.

Twenty years ago, I was stepping down with a geneticist friend of mine. We wrote a grant to use the blood spots, which we had access to because he knew the people up in Albany, to screen for one or two of the very common deafness genes which I had noted

and others finally did could be progressive. We were turned down three times for silly reasons. Okay, you don't win them all.

Ah-ha. However, about six or seven years ago, I get a call from a friend up in Harvard, says that Doctor such-and-such who I vaguely knew in China is trying to put together an article of how she had screened 50,000 children genetically and found there's one gene that makes them highly susceptible to aminoglycosides, could you help? So I re-wrote the article, and I'm now one of the authors on it, and really proof of principle showed that, okay, the hundred or so kids that carry this gene of the Chinese population now know that they can't get near aminoglycoside. There have been other attempts to do this, again, we have this whole business of how much information can be given or whatnot, but I would really think that this becomes important.

Another one of the battles I've lost, I've lost lots of battles. I think cochlear implants are great, no problem. They're a cure. However, I felt strongly that too much resource was going there, not only money, but people, brains. The real challenge was prevention and cure. That we now have the genetics to do this. I mean, people are still trying to regrow the ear and the cochlea, I think that's probably doable a long time down the line, but we have now the knowledge to really focus on, say, you make a diagnosis of one of the genetic diseases, make it very precise. There could be a substitution, a deletion, a deletion and substitution, a transposition, you name it, Heinz 57 varieties. But once you know that in a human being, you should be able to tailor a virus that would do something about it. The same thing with the sound trauma.

Another colleague now dead, Barbara Bohne, was doing beautiful work in this. She would notice the progression of things. I kept on saying, “Barbara, why don’t you begin to work on how to stop this once it starts, so they can regrow?” The same thing with finding the premature cell death of the mice, and the same thing in CMB disease, and later on when I came up to New York for the rubella. If you look at the fetuses that were aborted and you look at the temporal bones, everything was there. The virus knocked it out later on. So this is an area and I think you saw; I don’t know if they published that in the stuff that they did for the NIDCD. But this I think is an extremely important, and I think it’s low-hanging fruit. I don’t know who the new director will be, he or she, they may or may not.

**KH:** And we are going to get back to that too. I just want to go back a little bit more in time, and I wanted to ask you about – I believe you served on the advisory council of the National Institute of Neurological and Communicative Disorders and Stroke. This was while you were working in New York, but at the time it was called NINCDS?<sup>10</sup>

**RR:** I’m not sure. I know I served on the first council of the NIDCD. I probably did. I can check my curriculum vitae.

**KH:** That’s okay. I wasn’t sure if you have any memories of that, but if you don’t that’s okay.

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<sup>10</sup> The institute has since been renamed the National Institute of Neurological Disorders and Stroke.

**RR:** No, the head of the institute, Goldstein, was a good friend of mine. But yeah, that's another story.

**KH:** Okay. I wanted to ask you, my understanding is also that you served on a committee called the National Committee of Research. What was the affiliation of the National Committee of Research?

**RR:** Ah, yes. Okay, now we're getting to the core of the apple. So Eve and I are driving somewhere on a Sunday, I think it was, and I get a call on my cellphone, early cellphones in those days, from Dave Lim, now deceased. Everybody I know is deceased; it's no fun. "Bob, we have this thing called the National Council of Research, and I think we'd like to have you join this." Okay, what's the background?

Representative Natcher,<sup>11</sup> who was head of the House Appropriations Committee, was one good guy, despite his love of roads and lack of mass transit, but that's another story. The various people with neurological diseases, everyone would come up with a different thing, and Bill said, "No, this is useless, you're wasting time. You all ought to get together and do a thing." So the gal who put that together was Marjorie Guthrie. Who was Marjorie Guthrie? Woody's widow. Poor as a church mouse. So she put together this thing called the National Council of Research, and Mrs. Lowry (phonetic), who was in MS, and so were other people, they finally brought me onboard, and in six months guess who was chair?

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

Okay, so my job every year was to provide testimony to the House and the Senate, and part to this, we figured out early, would be to have some big personality come down to talk to make sure that the members of the House and the Senate showed up. So we did this, and I've had some great (inaudible 00:46:01), became great friends of various and others. What's her name? The actress, I have a picture of her. Did that. Yelled at the committee and so forth.

And so we're doing this, and we're getting pretty effective at this. After a while, I realized that what I was interested in, communication disorders, was getting the short end of the stick of appropriations and attention. So I said to myself, "We need a new institute." So I figured out how you do a new institute, and it was a little bit like shooting birds. You don't get the first flight, but you should get the second flight.

So I decided, let's go ahead. I had to do two things. First, I needed to have scientific justification. What I did was to organize this meeting, I can give you copies of these, in June of '87. I did this in Denmark, reason why most of the people were from abroad.<sup>12</sup> They all came, and we sat for seventy-two hours in a schoolhouse. I think one company gave us some food. And we put together this white paper, which essentially serves as the intellectual background.

The next thing that I needed for this was I need to have my organization behind me.

Jerry Goldstein, who was the executive director, was certainly happy with that, so we

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<sup>12</sup> The meeting was "Biology of Sensorineural Hearing Loss in Children," June 14-17, 1987, Holte (Copenhagen), Denmark.

formed the first ear, nose, and throat PAC. We only wore a white hat then, just for research; now it's your standard, hey, get the physicians more money. But this is the way I put it together, and it served its purpose. All this was well and good; however, I had no connections with Congress. I mean I had been giving testimony. That's not quite true, but I did.

Somebody comes who I sat in Deafness Research Foundation, Gerry Fox. And here's a little note to Gerry. Gerry knew that. So the next thing you know was Tom Harkin,<sup>13</sup> who was the sponsor of the bill, and we worked very hard to get it through the first, and here's all my testimony, and here is the critical letter from Teddy Kennedy.<sup>14</sup> And we get it through. This is how this was done; it was very, very fortunate. The whole language thing, I have this letter which I kept from the American Speech and Hearing Association, not language, trying to rationalize why we shouldn't have language in it.

They were totally wrong, because language, if you're looking at it, glioblastomas and epilepsy and myasthenia gravis and muscular dystrophy, language? (Laughter.)

However, in an institute of communication disorders, that's central. So the way I won that was we had a bunch of people putting together what should go in this bill, and I'm a member of the Cosmos Club, I think you know what that is. One of my friends out me in that because of all the lobbying I was doing. I said, "I'm paying for dinner, we're having language, it's as simple as that." And we have language. And then we had the first,

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<sup>13</sup> Thomas Richard Harkin served Iowa as a U.S. Senator from 1985 to 2015.

<sup>14</sup> Edward Moore Kennedy served Massachusetts as a U.S. Senator from 1962 to 2009.

here's all my testimony, this is the thing. And then these are the bills, and here is my introduction to the task force that met after we put it together.

**KH:** That's a great trove. So I'm going to ask you a few detailed questions.

**RR:** Hopefully I have answers.

**KH:** And if you don't, that's totally fine. I was wondering, why not work within NINCDS to try to change some of that support? What pushed you to think of a new institute?

**RR:** That's easy. Focus. The neurology institute covered too much. I broke away, they were smarter than we were. But focus. What I said to Jim Snow,<sup>15</sup> who never bothered to listen to me, Moskowitz<sup>16</sup> did it for a while, "Jim, what's going to happen here is you're unleashing a whole reservoir of people who were not focused. Now this is focused. Your pay level is going to be so high, that lots of grants that would ordinarily get, because it'd be so many good grants, you're going to run into trouble." And he did.

It's really like language. You have a whole institute which is now focused. If this was still a neurology institute, you wouldn't have newborn infant screening. You'd certainly have very little language. We've also picked up taste and smell, which is there. You wouldn't have people concentrated on that; very, very simple. And I think history has proven me right.

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<sup>15</sup> James B. Snow, Jr., M.D.

<sup>16</sup> Jay Moskowitz, Ph.D.

**KH:** So when you organized this conference, I have read that you said one unintended result was that you found out that research in Europe on hearing loss and communication disorders was more advanced at the time. Why do you think that was?

**RR:** Simply, where the publications were coming and the work was doing. There's a thing called the Inner Ear Biology Colloquium, which, when I was still running labs and things like that, I was in Europe every year. You saw what was happening in Denmark, Sweden, Germany, France, United Kingdom, Switzerland, and even to some extent Italy. They were beating us hands-down.

**KH:** Was that because of funding, because of opportunities to collaborate, all of the above?

**RR:** Funding. And also, medicine in Europe is not for profit. Medicine in this country by and large is. What I did at Einstein was I took a modest salary, I brought in lots of money from practice, and that went into laboratories, Tom Van De Water, Judy Gravel, and supported them. So it was a different climate. Also, promotion in Europe, if you wanted to become professor (inaudible 00:52:56), you had better have an awful good basic science background. So it's a totally different culture, and I was very comfortable in Europe and saw what they were doing. That's why I did it in Europe.

**KH:** I have a question about how NIDCD's research area came to include not just hearing and balance and communication disorders, but also expand even into taste and smell.

**RR:** They just gave it to us, Murray. (Laughter.) That's all. I really didn't carry much about that one way or another. I think that they're kind of often areas, and they're probably getting a little more attention in the NIDCD than they would in the neurology institute. So we're kind of, we don't have touch. That's still in neurology. So we're kind of special senses, but more than that, we're communication. So it just got tagged on, and we'll carry the load.

**KH:** I wanted to ask you a little bit more. When you met Mrs. Fox, were you both working for the new institute?

**RR:** She hadn't dreamed that one up yet. Yeah, I think it was deafness research, but as soon as I mentioned to her, her family had supported Claude Pepper,<sup>17</sup> knew him quite well, and she knew more about that process of lobbying than I did. And we got, in fact, I was just on the phone with her this morning.

**KH:** So you two were able to join forces?

**RR:** Oh, yeah, quite. We worked quite well together.

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<sup>17</sup> Claude Denson Pepper, Florida Senator from 1936 to 1951 and Representative from 1963 to 1989.

**KH:** And you had already been working with AAO-HNSF's ENT PAC at that point.<sup>18</sup> So you had a little bit –

**RR:** Oh, yeah. When I had looked at how to do this, I realized what we needed to have, which we didn't have. We had no lobby, so I needed the major clinical thing which was that behind me. Luckily, Jerry Goldstein<sup>19</sup> and I were good friends, and I think he saw what I saw as the PAC that I started as soon as we got the institute, they would still support the institute, but their energies would really go into bread and butter practice.

So one of the things that I did as soon as we did institute and whatnot, I left that so my footprint in Congress was a white hat guy, not a black hat guy. But there were some other interesting things, too. What's-his-name became head of the FDA, then wound up becoming the pediatric otolaryngologist to all the Washington staffers of the House and Senate. (Laughter.) There's some funny things that happened.

**KH:** Once you meet people, right? So I wanted to ask you about a couple other people who were involved. So, I don't know if I'm going to pronounce his name correctly, but Peter?

**RR:** Peter Reinecke. Tom Harkin, whose brother's deaf, became our supporter. Reinecke was originally Pepper's aide, then he was Tom's. Peter essentially wrote, we gave him what to go into the legislation. I'm not a lawyer, so Peter put that into "Congressese," so to say. And he's smart, and he knew what words to put in and what words not to put in.

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<sup>18</sup> American Academy of Otolaryngology-Head and Neck Surgery Foundation's Ear Nose and Throat Political Action Committee.

<sup>19</sup> Jerome C. Goldstein, M.D.

**KH:** I might have missed this before, but I think you've also mentioned a role for Dr. Joseph Miller?<sup>20</sup>

**RR:** No, I didn't. Gerry brought that up. Joe was certainly involved, he too is deceased just recently, in helping get together some of the physicians and scientists. One of the other things that I have here is we had a little trouble convincing the scientists of the association's research. We had a debate on that too. Some people were conservative; they were afraid of leaving the mother hen so to say. However, I think history has borne me out.

**KH:** And then, you might have mentioned today, but also Dr. George Gates?

**RR:** George was also useful in helping lobby, and he's now somewhere in Texas.

**KH:** Okay, great. I also wanted to ask about the demonstrations at Gallaudet University, and their role.

**RR:** (Laughter.) I'm a pack rat.

**KH:** I love it. I want all these documents.

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<sup>20</sup> Joseph Miller, Ph.D.

**RR:** Anyway, back on the ranch. I had good relationships with Gallaudet. In fact, when I did the thing in the New York Academy of Sciences, I actually had people from Gallaudet to talk about sign, to look at the cochlear implant, the whole thing with genetics. It seems that the board of trustees, which is a Congressional board, I think, tried to recruit a standard good administrator, and the Gallaudet population, faculty and students, said, “No, we want a deaf president.” And so they rioted.

Okay, so what happened with Gallaudet? They wanted a deaf president, and so they rioted in the streets, and that really brought attention there. Oliver Sacks wrote this very interesting article. Oliver was good friend too, and you’ll see some of his books are here. He’s acknowledged the information I’ve given him. He and I have a lot of things in common. A, we both like sushi. B, we both had ridden motorcycles as young men.  
(Laughter.)

**KH:** And neurology.

**RR:** Well, yeah, he’s a neurologist. I’m just an earwax doctor.

**KH:** (Laughter.) So there were a number of factors coming together with this legislation and trying to start the new institute. Was there opposition?

**RR:** Oh, yes. American Speech Hearing Society really. It was also some dirty pool, dirty tricks. I remember we were, one thing, some conference of NIH went on, and we were

told by their lawyer that the board of ASHA voted against it. That happened to be a lie, I was informed by one of my friends on the board. I think what ASHA was concerned about wrongly, was only that all the grants would go to MDs, and not to PhDs, not essentially to PhDs. And then they didn't want language. They thought this was wrong, stay in neurology. Again, I think we were proven. So that was the most vociferous and most difficult thing to manage. But we managed it.

**KH:** And those were splits within NIH and within the larger profession and the larger world of interested parties over what the institute should cover, whether it would hurt the larger research and funding, I mean, how would you characterize this?

**RR:** Not really. Most everybody saw it right away, that this was, we had the scientists. There were some who were worried that it wouldn't work. However, I think it became obvious to everybody, and also when you looked at the numbers, which I have detailed in one of my testimonies here, comparing with eye, it was obvious. I did my homework.

**KH:** And who were some of the strongest allies? I think you've mentioned some of them.

**RR:** It was Gerry, myself, certainly Tom Harkin, Pepper, Natcher in Congress, people at Gallaudet finally, yeah.

**KH:** And I read that at one point, the bill had 101 sponsors in the House, and when it came to a vote there only two voted against it. So it seems like it did become very popular.

**RR:** Yes, we did our homework, believe me.

**KH:** And was it a similar story in the Senate?

**RR:** I think so.

**KH:** Did you anticipate any challenges in having President Reagan sign the bill into law?

**RR:** At this point, no. When I was in Beijing, and I still have the cable framed in my library in my country home, that Reagan signed it. I think that at that point there was such an overwhelming Congress and the amount of money was small change, it was no problem and it was win-win all around. We really had very little opposition. It was just some people in American Speech and Hearing that didn't use the word language at that time that tried to cause us trouble.

**KH:** And how long, would you estimate, did you work on this project?

**RR:** I probably started worrying about this in the end of 1976, beginning of 1977. And by June of '97, [sic] I was certainly committed by pulling off the meeting in Denmark. So I would say from my initial homework in, say, January of 1997, to the adoption of the bill in whatever it is –

**KH:** I think by 1989 it was active.<sup>21</sup>

**RR:** Yeah, 1988. About two years, pretty much an all-time record. (Laughter.) Well, Gerry Fox had a lot to do with that.

**KH:** And so you stayed involved with the new institute. What did you do?

**RR:** I was on their senior advisory council until the term limited me out. Then I served on many of their review panels.

**KH:** I wanted to ask a little bit if you remember, I understand you were part of the task force of experts who helped create their first strategic plan in 1989. What was it like meeting with the experts to create that plan?

**RR:** They're mostly boys and girls I knew. Some didn't know who I was, so Chuck Berlin did this with me.<sup>22</sup> Chuck was actually one of my graduate students later on. So I sat in with the linguists. They were the happiest people there, and I have my address that I gave in opening this. So essentially, "We have this structure. Where should we go and what should do we do?" And that was a very interesting process which I've documented.

Also, what I don't have here is I have about 250 linear feet of my daybooks, where I write down what's going on. I'll give you a copy of the book I did of the history of the

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<sup>21</sup> President Ronald Reagan signed the legislation that created the NIDCD on October 28, 1988.

<sup>22</sup> Charles I. Berlin, Ph.D.

department; all that's documented in there. All that, by the way, when I become fertilizer, will be at Hopkins, including my library and all my professional papers.

**KH:** Oh, great. Well, as a Maryland person, that's great. Why were the linguists the happiest people there?

**RR:** Because somebody was paying attention to them. They had the spotlight on them. Also, I think another point here is, I've done a little bit in the history of linguistics, and have most of the significant books, some of them kind of humorously so. By and large, until the end of the twentieth century, linguistics was considered a philosophy subject. It was something God-given, unique to the great apes *homo sapiens*, and there are only a few like Beekman and others who really looked at language as a continuum through all the species. I've been highly criticized for that point of view and adopting it, but that's how it is.

This time we said, "Okay, hey, this is real. This is biological, this doesn't belong in the Church, and it doesn't belong in the department of philosophy." We have comparative languages. We have guys like Chomsky, who's caused more trouble than he's worth with his ideas based on nothing. I will be probably criticized for that statement, but I'm serious. Language is as much of a biological function as getting up in the morning and emptying your bladder. That gets a lot of people angry, but that's what it is. It has to be.

**KH:** That's fascinating. So I wanted to ask a little bit, the committee at the beginning of NIDCD was concerned with facilities for the new institute, and about research training for investigators. How were these issues addressed?

**RR:** Through money. (Laughter.) Again, I don't, I maybe have it back in my diary somewhere. Training became a very important thing, because we just did not have an army out there. So some other people, although I was in it early, I wasn't in administrative, we did the Association for Research in Otolaryngology. The midwinter meeting is our big meeting, so the first one we had was at the Happy Dolphin in St. Petersburg beach, and the people who were faculty and whatnot stayed on the ocean side, where the cockroaches were only this big. The graduate students were across the road, where the cockroaches were that big. And there weren't very many people. Again, I have all the programs at my library in my country house.

Now it has grown to where we'll have a thousand or so more presentations, and we go on with two or three simultaneous sessions. So here again, I was right. You wouldn't have had that growth if it stayed in neurology. And it's excellent science, and the organization is pretty democratic. I'll be there in Baltimore for three or four days, and actually I'll have another poster.

**KH:** So there was sort of a growing momentum after the foundation of NIDCD?

**RR:** It was a vacuum, and the vacuum, you know, it was like the California Gold Rush, or the Oklahoma Land Rush. That was open territory, and then of course you had some substantive, mainly in hearing, observations of what's his name and Rubel's,<sup>23</sup> the chick with regeneration of cells, so you had that stampede. You had a lot of people doing good, sophisticated science, then someday you have a real live scientific base. No longer is your up miles ahead. I would say the horse race is running, but if you look at the Lasker Awards, what's his name here, the Rockefeller won, our friend in France, the geneticist got another. And Fetty (phonetic) in the UK got another.

**KH:** I did want to ask what types of treatments or devices were available to people with hearing loss, deafness, voice, speech, or language problems when you first started your clinical work versus today, and how you think NIDCD has fit in.

**RR:** Well, first question, I also have a whole collection of their instruments. When I first started this, I guess in 1958, you had some very poor hearing aids, you had ear trumpets, and you just had a little habilitation for voice problems, almost nothing for speech, certainly nothing for language. Today, you have modestly sophisticated hearing aids, not as good as they can be. You have cochlear implant, you have a lot of things that can be done for voice. Speech is still training; the only interventions now for language are essentially habilitative.

But what role has the NIH played in this? Here we get into what I think is, the cochlear implant was really developed outside of NIH, much too speculative. And NIH then spent

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<sup>23</sup> Edwin W. Rubel, Ph.D.

a lot of money on it, but they locked the barn after the horse was out. NIH is safe science, but it does the building blocks. However, if you look a little bit further, the basic science underlying these things came from NIH and came tax-free. What bothers me so much is that the pharmaceutical and manufacturing companies are making a lot of money when the basic science that's let them do this has come from the taxpayer in two ways, either directly from a governmental grant, or, say at Einstein, where I am, where people have given tens of millions of dollars, they got tax deductions so that, you know, somebody could pay part of somebody's salary.

So I think that this is a social economic dissonance that has bothered me. Probably, and I may be wrong, one of the most important things NIH has done has been the newborn infant screening, to help that along. The second thing that it has facilitated is all the genetics. It's a leader amongst other leaders. The Institut Pasteur has probably done more, Karen Steel at Cambridge has probably done more, Di-EL (phonetic), but they have facilitated this.

**KH:** Thank you; that was a great overview.

**RR:** I think it's a little bit tunnel vision. There's probably more to it than I appreciate.

**KH:** I wanted to ask you about a few of the people involved. Again, Dr. Jay Moskowitz was the first acting director of NIDCD. I understand that was a shorter term, but did you work with him?

**RR:** Yes.

**KH:** What was he like?

**RR:** Highly workable. This was something totally new to him. Listened, facilitated, and was an excellent director.

**KH:** What particular challenges did he face?

**RR:** Setting up a whole new thing from nothing, which he did quite well.

**KH:** Are there any particular accomplishments?

**RR:** There's nothing I can remember specifically.

**KH:** It was setting up the institute.

**RR:** Yeah, that was enough. Organizing the conference we had. And listening to people.

**KH:** He was followed by the first director, who you've mentioned earlier today, Dr. James B. Snow. Did you work with him also?

**RR:** Yes.

**KH:** And what was he like?

**RR:** I've known Jim, when he was chair at Oklahoma, I was a resident; he had invited me out to speak. Then he was at the University of Pennsylvania, and then he went to NIH. Jim was his own man. I don't know how much innovation he did with the institute. When what's-his-name became director, he got rid of Jim. I thought that was unpleasant with what happened. He showed up briefly at Jim's going-away party. Jim had a job which probably nobody could succeed, for the very reason this has opened up a floodgate. He needed much more money, I tried desperately to get him. He got a heck of a lot more but still didn't cover it. Jim was very much into himself. He was not a social creature. He was an honest guy who really tried hard.

**KH:** So what sorts of victories would you say came out of his time, which would be the 1990 to 1997? He had a brand new institute.

**RR:** Again, probably the newborn infant screening. I don't know what else. I'd have to take a look at what was and was not funded.

**KH:** And then my last main question has to do with James F. Battey.<sup>24</sup> I understand he was scientific director starting in 1995 and then director. And you worked with him?

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<sup>24</sup> James F. Battey Jr., M.D., Ph.D.

**RR:** Yeah, and he just retired.

**KH:** Can you tell me a little bit about his tenure?

**RR:** He was great. Jim knew nothing about communication disorders, but he was a gene jockey, and made some substantive things. And he brought the institute into the twenty-first century. He was a very good listener, he interacted well with people, and all the genetics were started with him. A lot of the cell biology was started with him. He certainly encouraged things in language, he encouraged things in speech and voice, so he turned out to be a rather good, outgoing leader to steer the thing as best you could. He has accolades. I'm sorry to see him go.

**KH:** It sounds like he was very open to interdisciplinary work, and that that's very interesting.

**RR:** He also brought in molecular biology, which was the reason why he was appointed. He then applied this to the problems of communication disorders, which was needed. So this was exactly where I was ten years before in Denmark. I always get the Cassandra award.

**KH:** Were there any other researchers or staff members I didn't mention in the early years of NIDCD who you might mention?

**RR:** Well, Dave Lim for a while,<sup>25</sup> who's also deceased, did a very good job.

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<sup>25</sup> David J. Lim, M.D.

**KH:** What did he do there?

**RR:** He was scientific director, and he fostered, he was there with Snow, and I think for part of the time with Battey. I'd have to check out the times. He was the guy who implemented especially the intramural, and we saw a growth of really good science intramurally which they have now. I think that's mainly Battey and David Lim, did that and built this very good genetics and intramural structure.

**KH:** You've already discussed some of the great contributions of NIDCD in public health, infant screening, and in research and basic science. Are there any others?

**RR:** Well, I think the genetics, I'm not sure what's happened in voice and speech, or language.

**KH:** Are there any challenges you think NIDCD has faced and continues to face today?

**RR:** Well, I think fundamentally, go back to there, is to look at way of prevention and cure. Also, it's funny, I was just reading before you came in. I've been a great proponent my entire scientific life of the value of basic research for research's sake. Nothing more, nothing less. I think much of NIH is oriented to health goals, and perhaps NSF is a better place for this. However, with my original grants from NIH, a lot of this was basic science, and I think that there needs to be a message sent out from the NIDCD that yes, we're interested in basic, underlying science, that superficially may not have any

application to human disease, but looks at the basic building blocks. I think what we're seeing today, a total lack of that.

We're also seeing, I edit a national journal, I get to too many meetings, we're seeing people spending their time mining clinical data on national surveys, which really doesn't add anything, instead of looking at that really basic work. Hopkins was refreshing.

Although I'm not a vestibular person, while I was there touring their labs, there I saw about four or five laboratories asking very basic questions about the vestibular system.

Okay, this is an interesting neurological system, the answers to those questions are going to pay off fifty to a hundred years from now. They aren't very expensive, and this is where I think much of NIH has lost sight of.

**KH:** Very interesting. I just wanted to ask, if you sort of look into the future a little bit, what do you see in the future for NIDCD?

**RR:** Oh, I see in the future quite a bit. I see they will develop prevention and cure. I will see that they will begin to understand the biology of language. The two would be the two big things, so if I was director, and I was considered, I was asked to even put my hat in. I didn't want to because I'm not good at working for presidents and things like that. That's not my MO. But if I was the new director, I would put as much emphasis as I can into finding ways of prevention and fundamentally looking at the biology of language.

**KH:** What are some challenges it must overcome to do those things?

**RR:** The need for the leadership of the institute to articulate the needs of this and fund it.

**KH:** Switching gears again a little bit, do you have advice for a young person interested in making an impact in the lives of those affected by hearing loss and communication disorders?

**RR:** Yes. Pursue science. But today, you have the problem that all these young people have this huge amount of debt. And this is interesting. I'm a Princeton grad, and Shirley, who was president before the president incumbent, set up so nobody from Princeton graduated with a debt. So, some years ago, I was getting some piece of wallpaper from Hopkins, and brought this up at the dinner, and I thought the dean would kill me. So now that NYU has done this, we just got a letter from dean at Hopkins, saying, "Oh, why don't you contribute to this?"

Here I think that elite medical schools like Harvard, Hopkins, Stanford, University of Washington, both state of and St. Louis, several others, Yale perhaps, these men and women shouldn't have to finish with a quarter million dollars' worth of debt, because that's going to influence what you do. I was lucky. I had no debt, I was able to pursue science.

**KH:** So graduating with that amount of debt can hurt basic science research.

**RR:** Sure, because you're not going to do that. You've got to work that off. By the time you work that off, you'll be over the hill.

**KH:** Is there anything that I haven't asked about that you'd like to talk about?

**RR:** I think we've covered perhaps everything. Anything you can think of. I think we've looked at one person, myself, who felt very strongly. I then did some very deliberate things, including organizing and meeting with people, and some people said, "Ruben, you're crazy, nobody would come." Everybody came. Everybody came. They wouldn't miss out on this. So I've had an interesting life experience. Now eighty-five years of age, still thinking, I think it's succeeded, but it has a much further place to go.

I think the three places, concentrating on looking at prevention, genetically and otherwise, concentrating on what is the biology of language. Thirdly, allowing basic science, that is, just pursuing science for science's sake. The fourth thing too, we had a talk the other day, which I realized that a PI on a grant now is just shy of a few years for collecting Social Security. The history of science shows that most of the substantive breakthroughs were done by people under thirty. So I think there has to be a program which is looking at engaging people before thirty and giving them their heads. A lot of things like that are going to fall in for the journal of negative results, but the winners are going to be spectacular.

**KH:** That is very interesting, because you did mention mentoring earlier. I would be interested in what you have to say about what makes a good mentor.

**RR:** I don't have the foggiest idea. (Laughter.) And I do it. My class at Princeton set up a thing called Project '55, now called the Alumni Corps, and all the men and women from the graduating class who want to go in for not-for-profits, we have a little building down at Princeton, apply to us; we interview them. I do some of the interviewing. We take 10 percent of that, so that's 1 percent of the graduating class, and then the men and women who are in the New York area who are interested in medicine, biology, I get to mentor.

So what I've done here is once a month, we go out to lunch somewhere, but also see something because I know New York, which they may not, and we talk about what they're doing, where they want to go, and I just opened doors. But I was never mentored. So I think the men who I take care of were happy with it, and certainly the organization is. But I see all this mentoring, all this soft stuff going on. I'd much rather see somebody in the lab doing some molecular biology. (Laughter.)

**KH:** Well, thank you so much. I learned so much. I really appreciate your time in sharing this with us.

[End of interview]