



CMSC PODCAST

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“A Pillar Series” featuring Donald Silberberg, MD

Operator: The conference is now being recorded.

Ms. Dottie Pfohl: Welcome to this podcast for the Consortium of MS Centers. It’s my pleasure today. I’m Dottie Pfohl, and I’m Director of the Website Project.

And it’s my pleasure today to welcome Dr. Donald Silberberg, known to many for his work as Professor of Neurology at the University Pennsylvania School of Medicine.

Dr. Silberberg received his MD from the University of Michigan School of Medicine and has trained extensively, including the University of Michigan School of Medicine, but also trained in Neurology at the National Institutes of Health. He’s been a Fulbright Scholar. He studied in Queen Square, and is a fellow of neuro-ophthalmology at the Barnes Hospital.

Dr. Silberberg joined the faculty at the University of Pennsylvania School of Medicine in 1963 and served as Chairman of the Department from 1982 to 1984, and then as Vice Dean for International Programs through 2004.

Dr. Silberberg’s research has focused on the medical causes of neonatal injury and on multiple sclerosis and related disorders of the nervous system. A parallel focus has been on behalf of clinical neurosciences, with attention to child health and development in the developing world.

Because Dr. Silberberg's accomplishments and vitae are so long and his publications, we will offer a link so you can get to know Dr. Silberberg a little better that way without taking time here.

But, through the World Federation of Neurology, Dr. Silberberg organized international symposia, focusing on ways to improve the prevention and care of disorders of the nervous system in developing countries.

He also serves as an advisor to the National Institutes of Health, the World Health Organization, the World Bank, the National Security Council, the Department of State. He has served as the Editor-in-Chief of the Journal of Multiple Sclerosis, and serves on numerous editorial boards and has published over 300 scientific reports, chapters, and reviews.

So, it's a particular honor to welcome Dr. Silberberg. Hello.

Dr. Donald Silberberg: Hello.

Ms. Dottie Pfohl: I also personally am thrilled to have Dr. Silberberg with us today, because he has served as a mentor and inspiration to me here in the department where I work.

Dr. Silberberg, recently you gave a grand rounds, and you traced the history of the Department of Neurology here at Penn. And I must say that your perspective on it changed the way I view the department, although I have been--had the pleasure of serving in this department for 20 years.

Somehow, you brought the portraits on the wall and the plaques to life for me, and with a new meaning. So, I know that our conversation today will be particularly

meaningful to me, and I--it just gives great pleasure to introduce you in this way through this podcast.

Dr. Donald Silberberg: Well, thank you, Dottie. It's a pleasure to try to help with this.

Ms. Dottie Pfohl: Thank you.

Well, you've spent a number of decades on efforts to improve neurological care in developmental--in developing countries. And I'm wondering, how did you first--receive your first exposure to the needs of people around the world, in many cases so far away? How did that catch your direction?

Dr. Donald Silberberg: Well, the exposure began with international meetings in the 1970s, where I would be invited to visit clinics or give talks after international meetings. It got more serious as a result of a sabbatical experience at Pahlavi University in Shiraz, Iran, summer of 1974, at a time when the University of Pennsylvania and Pahlavi University had a very close relationship. Our university actually set up their School of Medicine in the early 1960s.

And I began to see the need, opportunities, see what a difference it could bring--it could mean to bring some training into situations where there was--there were practically no measures that were in place.

So, that's where I got serious.

Ms. Dottie Pfohl: Well, I know you espouse the interdisciplinary approach in comprehensive care for MS because, when I first came to the department, you explained to me the concept of comprehensive care and certainly have always fostered an interdisciplinary approach.

In the global work, it seems that you bridge not only scientific and medical disciplines, as well as the oceans as the mileage that separate languages and cultures. Are there particular qualities or skills or resources that you feel are needed to build these successful teams, either globally or within a department?

Dr. Donald Silberberg: Well, that's a very broad question.

Ms. Dottie Pfohl: Yeah.

Dr. Donald Silberberg: I think you've just named some of the skills. It takes a grounding in one or more of the disciplines, either in applicable research or in clinical skills, and a willingness to work with people from very disparate backgrounds, a willingness to get away from any concept of foreignness or the other, as it were.

Ms. Dottie Pfohl: Um-hmm.

Dr. Donald Silberberg: But, I can't pick out any--.

Ms. Dottie Pfohl: --So, no one particular model of organization might fit across the board, or is there something that you feel seems to work better in some places than in others?

Dr. Donald Silberberg: Well, I think simply the ability to be interactive, to talk to people, to explain sometimes complicated concepts in simple terms--.

Ms. Dottie Pfohl: --Um-hmm--.

Dr. Donald Silberberg: --Are all very valuable.

And, of course, for international work, it helps to have some understanding of how the body politic works, because there's often a huge relationship between what can be done in a country and what the Minister of Health or other officials will enable.

Ms. Dottie Pfohl: Hmm.

Dr. Donald Silberberg: It also helps to know what the resources are from the various funding sources, whether it's in the US or Europe or elsewhere. No one characteristic, just lots of different--.

Ms. Dottie Pfohl: --Well, I'm wondering, in neurology, if you can think of areas where there are the greatest needs, perhaps in terms of preventing disease or relieving suffering and disability. Can you think of three or four of what might be the greatest needs we face today in neurology?

Dr. Donald Silberberg: Well, if you're talking globally, it quickly gets into very large numbers for several kinds of disorders. I'll come back to MS in a moment--.

Ms. Dottie Pfohl: --Okay--.

Dr. Donald Silberberg: --Because there's a distinct and different kind of need there.

But, numerically, I mean, for example, epilepsy affects probably 60 million people in developing countries, and 90 percent of those people have never seen a medication. They're untreated. Their lives are ruined by their disorder. And this is happening at a time when, as you know, we have many low-cost treatments, as well as not-so-low cost drugs available. And for a variety of reasons, they just don't make it through to the populous. That's a huge issue.

Stroke is enormous. There's very little concept of stroke prevention, and almost none of treatment of acute stroke in most developing countries.

There's a huge overburden of neuro-developmental disorders, mental retardation, cerebral palsy, behavioral disturbances, language disorders, a lot of which is probably

related to nutrition, to head trauma, to a whole variety of causes, five to 10 times more common in developing countries than in the wealthy countries.

Those are some of the top issues. Head injury itself is a huge problem in poorer countries as compared to wealthy countries, much higher frequency of road traffic injuries, falls out of windows, and so on.

So, those--that's just a sampling.

Ms. Dottie Pfohl: Um-hmm.

Dr. Donald Silberberg: [Unintelligible--.]

Ms. Dottie Pfohl: --And how would you contrast approaches to MS in these various countries around the world? I know certain countries there's more prevalence than others, but anything [inaudible]--?

Dr. Donald Silberberg: --Well, you might be interested in an initiative that's going on with respect to MS right now as part of a bigger initiative. There's a concept of a global burden of disease, how to work out what is the economic, disability, mortality--burden isn't a good word, but the impact of all diseases globally.

Studies were done in 1988, '89 in preparation for a World Bank report in 1993. That is all being updated in project called Global Burden of Disease 2005, using data through 2005.

Ms. Dottie Pfohl: Um-hmm.

Dr. Donald Silberberg: And neurological disorders have been selected as one of the topics to be intensively reviewed, and multiple sclerosis is one of six neurological disorders that is being updated. And so, I'm involved with that. And part of what it

brings out is huge differences in the way MS is reported, approached, thought about from one country to another where it's common--.

Ms. Dottie Pfohl: --Um-hmm--.

Dr. Donald Silberberg: --The differences between, for example, Central European countries, Eastern European countries, and Western Europe or US. There are definitely needs in many of those countries.

Ms. Dottie Pfohl: I know you've advised medical societies, as well as the US government, for many years on these international health issues, including issues in, so to say, how--hot spots around the world. Are there any memorable experiences that you would like to share with us, or lessons you've taken away from traveling the world over? I know you're--seem to be traveling a lot, but you always come home safe and sound. But, have there been any--over the years, any experiences with such issues?

Dr. Donald Silberberg: Well, I do my best to stay healthy, whether it's here or traveling. The--I don't think you want to hear about personal experiences with the things that befall all of us.

I think one of my favorite experiences actually was in Iran, outside of Shiraz, in 1974, where I had the opportunity to visit villages outside Shiraz with a--an OB resident who was supervising village health workers who had been trained at the university for six weeks to six months. They were experimenting with different training periods.

And to see fantastic people with--who had been selected as having less than a high school education, so that they would not be upwardly mobile, and chosen by their villages, diagnosing epilepsy, trachoma, cervical disc disease, with just a minimum of training and supervision, I mean, that--really inspiring.

It's an example of what can be done, and one of the approaches to try to make things better in countries where there are very few professionals.

Ms. Dottie Pfohl: Um-hmm.

Do these kinds of international opportunities to collaborate continue despite some of the problems we've had around the world, either politically or with conflict?

Dr. Donald Silberberg: Well, yes. The--I have not--if what you're asking is have I had any personal experience with war zones, I have not done that. I have not been involved in countries that are actually in armed conflict.

But, short of that, there's an amazing lack of politics in all of this. It's very easy to talk science, talk medicine, do things together with people from almost any country--.

Ms. Dottie Pfohl: --Um-hmm--.

Dr. Donald Silberberg: --If one does not make the politics the--you know, the primary concern.

Ms. Dottie Pfohl: Sure.

Well, that's certainly been my experience here, having the pleasure of working with professionals from all over the world and the commonality of people. And I remember asking two young ladies who had traveled the world for a year, just for the experience, and asking them if there were any surprises. And they said the biggest surprise was that it was so easy, that people are, for the most part, very hospitable and helpful, and that they managed quite well, two young women traveling the world.

But, you've also taken your work through communication media, not unlike what we're doing today, but certainly in print. Your editorship of Multiple Sclerosis is of particular importance to us. We have a journal, the International Journal of MS Care,

which is currently being edited by Dr. Lael Stone of the Cleveland Clinic. And, of course, that journal was founded as an online journal by Bob Herndon and then went to print.

Do you have any thoughts or advice for Lael as she ascends the reins of editor of our journal? We are an interdisciplinary organization, so it's a bit of a challenge to have something for everybody in a journal like that. But, I'm just wondering, as an editor and someone who's been so acknowledged for your work, if you have any advice for us?

Dr. Donald Silberberg: Well, I don't want to call it advice.

Ms. Dottie Pfohl: Okay.

Dr. Donald Silberberg: But, just some thoughts. I think that--.

Ms. Dottie Pfohl: --Um-hmm--.

Dr. Donald Silberberg: --What people are looking for today, whether it's a neurologist, neurological nurses, physical therapists, patients and their families, what they're looking for is the highest quality evidence that they can find to back up any course of action, whether it's making the diagnosis or deciding how to treat or deciding what form of rehabilitation is appropriate, looking for good evidence.

Ms. Dottie Pfohl: Um-hmm.

Dr. Donald Silberberg: So, I think that--I mean, the focus has to be on finding authors who will, you know, contribute articles that back up whatever is said with really good evidence to support the thought. And that's not advice.

Ms. Dottie Pfohl: Um-hmm.

Dr. Donald Silberberg: I mean, that's pretty obvious for a good journal.

Ms. Dottie Pfohl: Um-hmm.

Dr. Donald Silberberg: But, it's--so, that's important.

Ms. Dottie Pfohl: Yeah. I want to shift gears just a little bit. I was reminiscing, in preparation for our conversation, about a grand rounds that you gave many years ago, and people were talking about the disease-modifying therapies that we have on the market. And I remember you looking at the effectiveness and the results from various studies and making a comment that it was interesting to you that all of them seem to come in in the 30 percent range. And I remember you saying, "We're doing something, but I'm not sure what."

Can you take just a few minutes, having gone through a time treating people with MS when we didn't have treatments, actually, therapies that could modify, now to where we have a whole battery of choices to work with? Just has your thought changed or evolved any on what it is we are doing with therapy?

Dr. Donald Silberberg: Well, it's evolved a little bit with the evidence, with the science, but I would think I would come close to making the same statement.

I mean, what's very clear is that we can reduce the number of clinical attacks. We can somewhat reduce actual development of disability and so on, within a narrow range. It used to be sort of around 30 percent. Now, it's up to maybe, depending on the study, 35, 40 percent, sometimes 60 is claimed.

Hard to make the comparisons between one study and another, because each is done in a different way and then they're usually not head-to-head studies. And there are theories as to why each different treatment works, whether it's modifying a T-cell lymphocyte subset population or whether it's--you know, whatever it's doing. The

problem is that we don't know the relationship of those actions to what it really is that causes in each multiple sclerosis [unintelligible.]

We're still operating sort of at the margin, not really understanding the disease mechanism. And that's why, my knowledge and my way of thinking, the research to try to understand the disease itself is critical. And I don't think we'll get a lot beyond where we are without a much better understanding of what is actually going on in MS.

Ms. Dottie Pfohl: Well, certainly having drugs on the market has changed a lot of things, introducing the private sector in ways that, you know, have undergone change and raised some controversy, etc. And yet, the influx of enthusiasm and money because of industry has certainly supported a lot of interest and new people joining in this endeavor to find cures and understand the disease of MS more.

Dr. Donald Silberberg: Absolutely. It's wonderful.

I think the early success in persuading third-party payers and the public to pay a high price for beta-seron--that was really the first--.

Ms. Dottie Pfohl: --Um-hmm--.

Dr. Donald Silberberg: --Was a huge gift to the MS population, because it brought in private companies who were willing to invest more and more in the field. So, it's absolutely a correct point.

Ms. Dottie Pfohl: Um-hmm.

Has this kind of advantage been seen around the world, particularly in the developing world?

Dr. Donald Silberberg: With respect to MS specifically?

Ms. Dottie Pfohl: With a respect to MS and the availability-- 'cause I know even in some highly developed societies, like some of our British colleagues, have a much harder time securing medications. I shouldn't say that.

Dr. Donald Silberberg: [Unintelligible]--I'm sure you're aware of the fact that the Ministry of Health in the UK was really unwilling to provide immune modulators for a period of several years until they were persuaded otherwise.

Ms. Dottie Pfohl: Yes.

Dr. Donald Silberberg: It's an even bigger problem in developing countries. I mean, it's--the cost is--can become a huge percentage of the total health budget. So, they have to be very, very careful.

Ms. Dottie Pfohl: Yeah.

Unfortunately, in my own practice, not a week goes by that I don't get many, many calls from people who have either lost their insurance, or their copay has been raised to a point they can't afford it or--I mean, it's just a very difficult situation here.

Dr. Donald Silberberg: Yes.

Well, you have with countries that have no health insurance--.

Ms. Dottie Pfohl: --Right--.

Dr. Donald Silberberg: --Or that have national schemes but are very concerned about overall costs.

Ms. Dottie Pfohl: Um-hmm, um-hmm.

You know, you are known for having a unique and a very keen sense of humor. How important has that sense of humor been for you in facing challenges and making friends around the world?

Dr. Donald Silberberg: Well, I--that's a very nice compliment. I think it certainly helps. The--you know, the ability to sort of look at what one is professing or what one is hearing with a little bit of humor often helps to make people comfortable.

Ms. Dottie Pfohl: Sure.

On a personal note, I'm wondering why did you choose MS? What got you involved or interested in people with MS?

Dr. Donald Silberberg: It was actually my neuro-ophthalmologic training that headed me in this direction, because I saw optic neuritis as a major issue within neuro-ophthalmology and neurology.

And I was offered the opportunity to come to Penn by Milton Shy. Part of the offer was, "Would you take over the second oldest MS clinic in the country"--it had been started in 1967. I got here in 1973--"And see what you can do with it?" And, I said, "Of course, with pleasure." And that was how I got started.

Ms. Dottie Pfohl: You know--and I know you're very active and have been over the years with the MS Society, at many, many levels.

Dr. Donald Silberberg: Um-hmm.

Ms. Dottie Pfohl: I'd also like to thank you for having personally sent me to June Halper. When I first came to the clinical role from the university, you encouraged me to meet June and, for me, the rest has been history.

Dr. Donald Silberberg: Um-hmm.

Ms. Dottie Pfohl: I recently was with June, and there was a nurse sitting at her right, a young nurse looking very intimidated. And I patted her and said, "No, no, we've

all started in that chair.” So, I can't thank you enough for having done that for me personally.

Dr. Donald Silberberg: Well, you're very welcome. You're our star pupil.

Ms. Dottie Pfohl: But, on a final question, we've talked a lot about MS here and around the world. I'm just curious about your calendar. How--are you already booked for the next year?

Dr. Donald Silberberg: Well, during 2009, I have overseas--I think that's what you're referring to--I have a workshop in Uganda in August, a meeting of the Global Forum for Health Research in Havana, Cuba; in November, going to India sometime in between, probably September or October--.

Ms. Dottie Pfohl: --Right--.

Dr. Donald Silberberg: --For a meeting of our collaborative study of neuro-developmental disorders in India with ImClone. So, I don't know if that's booked, but--.

Ms. Dottie Pfohl: --That sounds pretty booked to me.

Dr. Donald Silberberg: I think it's enough for me, yes.

Ms. Dottie Pfohl: Well, our producer, when we were preparing for this,, called you the Indiana Jones of Neurology, so--.

Dr. Donald Silberberg: --Oh my goodness.

Ms. Dottie Pfohl: But, on--just on a closing note, besides thanking you, I would like to put some links on the website for the Global Forum Health and with some of your background information.

But, besides just thanking you for the time and effort it's taken to be with us now on this recording, I like the commercial seen on American television on the network,

where you see the technicians and, behind them in a triangle, are the hundreds and hundreds of people behind.

And would just like to personally thank you from the healthcare professional standpoint for standing in front of us with a network and being such a leader, but also for the patients, because, over the years, I've known some of them, but you are so beloved by your patients and you really there are--are there for all of them as a resource. So, much appreciation from me, from the Consortium of MS Care, and all those that you've helped so much over the years.

Dr. Donald Silberberg: Well, thank you very much, Dottie. It's been a pleasure to speak during this interview, and I'll help in any way I can from here on.

Ms. Dottie Pfohl: Well, thank you so much, and look forward to working with you.

Dr. Donald Silberberg: Okay.

Ms. Dottie Pfohl: See you in the hallways.

Dr. Donald Silberberg: Thank you.

Ms. Dottie Pfohl: Bye-bye now.

Dr. Donald Silberberg: Bye-bye.

Ms. Dottie Pfohl: Okay.