

“The First World Parkinson Congress”
An interview and perspectives, February 18, 2006

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Our profound thanks to Dr. Federoff for both his time, just prior to the start of the first World Parkinson Congress, and the depth of information provided during the interview. The intent was to gain insight as to the scope of the Congress and thus to better prepare a summary of the Congress to share with others also afflicted by Parkinson’s disease.

Our personal plans would take us to the full Congress, from February 22 to 26, in Washington and, since many support group members could not attend, I wished to share what I could. It was in that spirit that I asked for the interview. In addition to the interview, Dr. Federoff has agreed to provide an opportunity to the Parkinson’s Community to hear his views on the Congress and the future of research at our Parkinson’s Fall Symposium at the Radisson Hotel September 16, 2006.

What follows are key excerpts of the interview. For those wishing to gain further insight, I strongly recommend the University of Rochester Medical Center web site for current work of the Institute, Centers, Programs and core functions of URMC, and of the nation’s premiere researchers, such as those in stem cell science as a an initiative toward restoration of cellular function, of those in ongoing clinical trials managed by the Parkinson’s Study Group (PSG), and, of novel methods that show promise, through molecular signatures, the hope to provide early detection and treatment with completely new interventions for future generations.

In addition to what will be seen as the pivotal role of Dr. Federoff as both contributor and, moreover, Chair of the Program Committee, there were nine other physicians and scientists representing URMC, its world-class research team and the interests of Caregivers and Patients. Not only did they provide science on their own terms, but a path forward for an international and diverse team of younger clinicians and scientists who will define and, no doubt attain, the goals to restore health and dignity to our lives.

The last piece to the puzzle can be found in the publicly-accessible federal legislative web site Thomas.loc.gov, where one can assess the current status of federal legislation so critical to the mission of URMC and future generations of those faced with the devastating specter of an incurable and progressively degenerative disease.

For a complete overview of the Congress, visit its website; forms for ordering audio (CD format) can be obtained by contacting the service provided to the World Parkinson Congress at www.aven.com.

I. Statement: Theme Selection Criteria

The objective is to provide a synopsis of the Congress for our Fall Parkinson’s symposium at the Radisson. In your introductory remarks in the final version of the program you discuss the use of themes to establish the objectives for each day.

Q1: With only five days and eight hours per day, how did you and the Steering Committee decide which themes to select – could you please review the ones you did include, how you decided upon the ones you did and the significance of the order in which they are presented?

Dr. Federoff:

The overarching goal was driven by a discussion with the head of the National Institute for Health (NIH) about four years ago that developed as a mission, under one of the premier clinicians for Parkinson’s, Dr.

Stanley Fahn. From the core team developed the concept of a Steering Committee, whose membership numbered about 20 of the world's preeminent scientists and clinicians.

The mission then evolved into one of developing a template similar in concept to that employed by our colleagues in the AIDs community. A further goal of whom to include at the Congress was defined to be inclusive of Clinicians, Scientists, Health Care providers, those involved in Advocacy and PD Patients and Caregivers.

As I began to assume responsibility for directing the program (Dr. Federoff became Chair of the Program Committee), we began meetings to define the content of the program.

We then began about a year and a half ago to map out an integrated program on the basis of posing an essential question for each day, structuring the presentations around the question, so all the facets that represented the different types of answers could be integrated into the program for that day. At the end of the day we featured a wrap-up plenary session of all the chairs for the sessions so that we could digest and distill and make as plain as possible the summary content of the day.

As we moved along, some extraordinary things happened that none of us thought possible. During a Berlin PD meeting, several Program Committee members met photographer who is also an historian. This evolved into a PD performance and an unique collection of images planned for the Congress for the history of Parkinson's as a visual display. We also have a staff person, Sharon Stone, who knew of a dancer who developed PD. (Ed. Note: Melanie Maar's performance was, in retrospect, was an act of sheer courage and nothing short of breathtaking.) From there we added visual art and poetry.

The resulting program is so densely packed that there is almost something for everyone at any time, especially when so many come for so far. Moreover, I knew that there would be different types of expertise represented, so we wanted the highest skill level of a given discipline at all times.

Break the day down by starting with a plenary session for all conferees and follow with symposia that are content-laden and then we bring them back, but we also have workshops that are far more interactive, where we hope the facilitators will help bring the audience and presenter together.

Ed. Note: In the final program, presentations were typographically color coded, with six colors representing seven sessions, preceded by a statement of theme as basis for the day. The day began and ended with plenary sessions to highlight and summarize the key points of the intervening sessions, which were conducted as sessions or symposia, with a chairperson and two to four presenters with research in support of the main topic; these were designed to appeal to scientists or those involved in care delivery whose roles range from professional therapies to spousal caregiving. Still others are designed to provide support for issues of intimacy or self-expression through art, music, dance or poetry.

Q2: There are almost 300 speakers from 27 countries supporting the Congress. How did the international nature of the Congress influence which themes were selected?

Dr. Federoff:

We had people on the steering and program committees from multiple countries and many who are world citizens, knew everyone and made clear who we could rely on in a particular city or country to give us the best of what they had. We reached out to them early allowing them to orchestrate interactions throughout the world, saying first, are you interested; next, who would you propose and, finally, what is it likely they would bring to the meeting,.

We also wanted to balance by gender and age, to showcase the younger contributors, be they clinicians or scientists – this is the field they are progressively going to inherit, and we wanted them to feel comfortable being that next generation.

II Statement: Objective

In your statement, you expressed a desire to serve the needs of

- patients
- caregivers
- clinicians
- allied health professionals
- scientists

Q3: On page 14 of the program, you list eighteen learning objectives for the last three groups. How did you decide on these objectives? (Remark upon the creation of measurable objectives for each of the three groups).

Dr. Federoff:

The people on the program committee, Dr. Fahn and I labored over trying to parse the most important information that could be extracted from a day's presentation and capture that succinctly is not trivial undertaking.

What we hoped for was that the most objectives would be clearly understood by a particular discipline, while others might find them a little less relevant to what they do but even if they understood one aspect that it would be of benefit to them. It would make me feel that the meeting on that level was a success.

Q4: How did you decide what to include and what objectives were appropriate for patients and caregivers? This group is less well defined as a target population compared to a person in a given medical profession.

Dr. Federoff:

On the Program committee, we have several persons who helped determine what objectives were reasonable. I think we are going to learn a lot by collecting information from this meeting and applying it to the next meeting in June '09 at the WPC in Paris. We had a lot of input from Parkinson's patients via the Caregiving Committee. (Moreover)...there will be things that Dr. Fahn and I will learn from the experience of going through it – observing, listening and connecting to use in '09.

III Statement: Stem Cell Research for Patients and Caregivers

There is much controversy over the use of human embryonic stem cells, but they appear to offer hope for more than just symptom management. I take 31 pills a day and, at the moment hope for a transdermal patch to make the delivery more consistent and wait patiently for a breakthrough.

Q5: The Congress addresses “The Future of Stem Cell Therapy” at the level of the professional. What is available for patients and caregivers? I attended one of Dr. Goldman's lectures and naturally found it barely of use to a non-professional. What sessions does the Congress offer for patients and caregivers?

Dr. Federoff:

I felt it was necessary to include a session on Stem Cells and we have some of the best people talking. In addition to Steve Goldman, we have Clive Svendsen and Ron McKay. This field, although controversial, offers a biological reality that currently cannot be approached by any other type of research – in effect closing the door and leaving it unclear to clinicians and scientists as to whether it even would have worked, would be a mistake.

The substrate upon which the opposition strives for us to do research predetermines the outcome. With proper science, we should migrate into early stage clinical trials in a year or two. As for a workshop on Stem Cells for Parkinson's patients and Caregivers, there are a lot of communities where this is being discussed and not just for PD. Stem Cells, while an exciting therapeutic opportunity – it's the ES (embryonic stem cells) versus the adult stem cells that's the crux of the issue, and we didn't think it was PD-specific. (At this point, I mention the public debates by UR Geneticist Dr. Mark Noble and his attempt to debunk the use of specious information and claims to the effectiveness of Blood-Cord vs. Adult vs. Embryonic Stem Cells. Dr. Federoff states at this point the need to be "critical and rigorous, especially if it is exciting until it has been replicated and others understand its potential.)

IV. Statement: Stem Cells and Tumors (Dr. Goldman)

There was a recent article about the U of R using adult stem cells from bone marrow for restorative work upon heart patients (6 at U of R). Dr. Goldman spoke of current risk level for embryonic cells in terms of tumors. This is not the same concept as "rejection", since stem cells are rejection-free, but with a propensity for tumors.

Q6: Is Dr. Goldman's work with embryonic, adult or blood-cord cells?

Dr. Federoff:

Dr. Goldman works on several different types of stem cells.

1. Embryonic brain (not stem cell) derived progenitors
2. Adult-derived progenitors
3. Human Embryonic Stem Cell

For HESC work, he is investigating the means by which the cell can be controlled prior to differentiation, so we can learn how to make a given type of cell.

Q7: What approaches are available to deal with the tumor risk and what would be the likely source of funding for such work, given the federal roadblocks, i.e., no funds from NIH based on the Bush policy. Would funds come from private industry (pharmaceuticals) or state programs be available?

Dr. Federoff:

If you take a sufficiently large mass of human ES cells and you don't differentiate them and **transplant** them into the brain, they form what's called a teratoma, which is a germ cell **tumor type** – it's a very immature tumor where they can differentiate into ectopic (displaced) tissues such as bone and teeth. So what's being done is, and a lot of groups are keen to work through this **methodology** is to guide the differentiation, opening up the field for clinical trials.

V. Statement: URM C Presence at WPC

URMC is providing a strong presence at the WPC. Besides you, there are contributions from nine other physicians and scientists. The Research link on the URM C web site lists a combination of 33 Centers, Groups, Programs and core facilities.

Q8: What does the URM C team bring to the WPC and where does Dr. Shoulson's PSG fit into the Congress? Surely with so strong a representation, contributions include a broad range of disciplines and interests.

Dr. Federoff:

The URM C was strongly represented by many outstanding scientists and clinicians. Those listed provided the accompanying symposia presentations:

1. Kevin Biglan, M.D., M.P.H.:

- “Enhancing Translational Research”
2. Howard Federoff, M.D., Ph.D.
“Cutting Edge Technologies to Understand PD/Biomolecular Profiling to Ascertain Molecular Signatures of Disease”
Chair: “Novel Therapies”
 3. Steven Goldman, M.D., Ph.D.
“The Future of Stem Cell Therapy/Selective Generation, Use and Pitfalls of Human Dopaminergic Progenitors
 4. Karl Kieburtz, M.D., M.P.H.
“Modalities for Following Disease Progression/Clinical Measures of Disease Progression.”
 5. Roger Kurlan, M.D.
Chair: “Symptomatic Therapy for Non-Motor Components: Sleep Disturbances, Depression and Dementia”
 6. Kathleen Maguire-Zeiss, Ph.D.
“Alpha-Synuclein: Animal Models/Synuclein Overexpression: Presynaptic Dysfunction in a Parkinson’s Disease Model”.
 7. Jonathan Mink, M.D., Ph.D.
“Basal Ganglia Physiology and Pathophysiology/Basal Ganglia Function With and Without Dopamine: The Importance of Focus”
 8. Bernard Ravina, M.D.
“Translational Approach to Neuroprotection Potential for Nicotine in Parkinson’s Disease Therapy”
 9. Irene Richard, M.D.
Chair: “Co-Morbidities in PD”.
 10. Ira Shoulson, M.D.
Chair: “The Role of Patients in the Development of New Therapies”

VI. Statement: New URMC Researchers vs. Parkinson’s

The web site states that 50 researchers are being added to URMC.

Q9: What percentage of the 50 are targeted for work on Parkinson’s disease and types of programs are being funded for PD?

Dr. Federoff:

We have actually added about 70. I recruited about 15 people and three of those have left to go on to become Chairs at other institutions.

Of the 70, approximately ten are working on projects to do with neurodegeneration.

My goal is to bring talent to Rochester so that URMC is viewed as the national leader in novel therapies to affect the history of disease, draw patients here from all over the world, and to create a cohesive and extremely vibrant model that links education, research and clinical care, a model to be emulated by others.

VII. Statement: Legislation Issues

There are a number of bills at the state and federal level that will affect research, particularly for Stem Cell research.

Q10: Which of these have you personally lobbied for at either level and where do you see the greatest chance for success for Parkinson’s research?

Dr. Federoff:

I have been involved with PAN and Joan Samuelson has also been a great lobbyist. I met with legislators in 1995 to help obtain funding for Parkinson's research for DoD. Funding now stands at over \$170 million after having first started in 1996. I do feel that the current emphasis on bioterrorism comes at the expense of national health. Funding provided by NIH has actually been reduced and has undermined our ability to remain a leader in biomedical research. This will affect the next generation of researchers because it is becoming much more difficult to become successful.

In the program, we have people who will discuss how other nations are dealing with the issue. On the one hand, we are similar to others in that our research dollars disappear in whim and, on the other, it has been skillfully exploited to create an impenetrable wall so that you cannot ask the important and critical questions – PD and AD constitute 5 to 6 million people at present, and with the age-dependencies, they will grow to be the single greatest health burden in the next 20 years. It is a massive societal problem and yet it has not risen to the level it needs to be properly addressed.

VIII. Statement: US vs. International Stem Cell Research

Much has been said about where we stand in the USA vs. the rest of the world in embryonic stem cell research. Dr. Noble has spoken highly of the Parkinson's work of Dr. Anders Bjorklund involving HESC; the UK is making great strides and Israel's researchers, benefiting from the foundation of religious tenets regarding conception, show promise as well.

Q11: Are we losing researchers to other nations?

Dr. Federoff:

The loss is quite small. What is happening is that the control of some research for stem cells has shifted to the state level. The President of the University of Rochester, Joel Seligman, and others, are driving the issue of research funding in New York; what's happening in New Jersey is healthy and a lot of foundations are investing monies in the direction of HESC lines, particularly in the area of Juvenile Diabetes. The Howard Hughes Foundation is funding creation of new stem cells **lines** and making lines available to people who want to work on them. The scandal in Korea is an unfortunate setback for the entire world, but the scientific value of the work will eventually accrue to other researchers. Work on applying adult stem cells (mesenchymal stem cells or MSCs) to heart attack victims in hopes of reducing the damage from scar tissue is proceeding.

Ed Note: On mesenchymal stem cells: A human embryo starts with one cell that divides to become many. Early on, stem cells change, or differentiate, from non-specific precursors into specialized cells that make up organs. Within a layer of the embryo called the mesenchyma, for example, mesenchymal stem cells (MSCs) can go on to become either cartilage, bone or muscle cells, depending which genetic signals they receive. Some MSCs persist beyond the fetal stage into adulthood in the bone marrow, where researchers believe they await the call to differentiate and replace damaged tissue. (From the UPMC article on Craig R. Narins, M.D., assistant professor of Cardiology and Principal Investigator).

IX. Statement: Future Goals

The next WPC is in France.

Q12: What goals have you set for research between now and then? How will you measure the achievement of those objectives?

Dr. Federoff: *“...That would take many hours...”*

Early detection of PD: In a research program I started two years ago (using white blood cells vs stem cells), we are looking for molecular signatures as a presymptomatic indicator of a predisposition of a person to PD, in effect, a biological marker akin to an “early warning sign” as in cancer diagnosis. We are able, using

robust modeling, to now differentiate among PD, AD and control groups. With further work, we hope this will open up a whole new class of therapies, one that uses something other than agonists (although some measure of relief is hoped for in the use of the transdermal patch – Ed.)

X. Statement: Creativity and URM

The role of creativity as a weapon against Parkinson's cannot be underestimated. As a new member of Frank Judge's Rochester Poets, I have been in contact with Chip Spann of the Sutter Medical Center in Sacramento, where he heads the LAMP (Literature and Arts in Medical Practice) program, in which patients participate in poetry workshops as a means of coping with their life situations, not all successfully. He has written a book, Poet Healer, which captures the work of many patients. In addition, I have been honored to be among the presenters of Essays and Poems at the WPC.

Q13: What types of programs similar to Chip's are in practice at URM?

Dr. Federoff:

I know a bit of Chip's work. You know our fourth mission is really community. I think if there was something we could do to take advantage of some of the things that you and some of the others in the Parkinson world are doing and sort of open it up as an example of how the URM contributes to community, that would be spectacular. If I can help in that regard, I'd be happy to do so. So we can figure out how to do that.

XI. We would deeply appreciate your support of the Fall Symposium as an invited speaker on the first World Parkinson Congress. Please join in sharing our common hopes.

Dr. Federoff:

I'd be happy to support the symposium. Just provide me with the dates.

In closing, I wish to thank you again for your valuable time and wish you and your team every success.

Gary Hilburger