

The Vision Becomes Reality: NEI Accomplishments and Goals for the Future

Dr. Paul Sieving, Director, National Eye Institute

Brian, Katrina and Bill, thank you very much for those words on Jules Stein. I think it would be appropriate, now, to reflect for a few minutes on what has developed out of Dr. Stein's vision to create a National Eye Institute.

When we think back 45 years ago, we can remember the desperate times for people who had age-related macular degeneration, diabetic retinopathy and cataracts. Cataract surgery is a simpler thing now. You go into an outpatient center and three hours later you emerge. A day later, you are back at work. That is a remarkable accomplishment.

Forty-five years ago, after a diagnosis of diabetic retinopathy, five years later half of those patients had become blind. Now, it is actually a challenge to find individuals who are blind from this disease. It is truly a remarkable time.

For most glaucoma patients, today's treatments are fairly simple. You lower the eye pressure in glaucoma, and you slow the progress of the disease, preserving sight. Of course, with the knowledge we have gained through research, we have also discovered new complexities and it turns out that there are a substantial number of individuals with glaucoma whose pressure is normal – a condition called normal tension glaucoma.

So we will have to think about these diseases in a very different way, diseases that 45 years ago were the scourge of individuals as they grew older. Now, courtesy of Jules Stein, his legacy, and the work done by many people supported by the National Eye Institute who are sitting here today and many, many more on the outside, these conditions have been held at bay. I choose those words, 'held at bay,' because I think that we are at a very interesting time in medical history.

As I view it, the history of medicine will come to be seen as divided into two periods: before 2001 and after 2001. The year 2001 marks the identification and elucidation of the human genome. From 2001 to 2003, there was a wave of announcements celebrating the completion of the human genome. It is that genome that, in fact is changing the very face of medicine.

By 2005, the first gene was identified as conveying significant risk for age-related macular degeneration. The NEI's Dr. Rick Ferris was part of the group that published that. As an attestation to the strength of the vision research community, there was not just one report, but in fact there were three reports by independent groups in the same journal of *Science*. Another followed in *PNAS* shortly thereafter, so we had four independent reports identifying and then confirming and reconfirming that genetics plays a major role in age-related macular degeneration. Now, only seven years later, we are up to at least 19 genes that cause AMD. The challenge in front of us is how to ameliorate AMD—how to address AMD in fundamental ways through this ability to identify genes.

Diabetic retinopathy. Again, people here in the Eye Institute, and people supported by the Eye Institute, have played a major role in understanding how laser photocoagulation can retard or even ameliorate the devastation caused by new blood vessels growing in the eye driven by the underlying condition of diabetes. Today, diabetic retinopathy blinds far fewer people. When it does, it is because of social circumstances, primarily.

We have great opportunities in front of us. Opportunities that Jules, I think, would appreciate as an entrepreneur. Opportunities to take what has been garnered through 45 years of work and apply it in a directed fashion to getting to the root causes of disease, and ultimately to treating those conditions in a foundational way. Ultimately, I think we can look forward to a century of preventive medicine, catching the symptoms of disease before they have devastated vision. All of this, I would say, is courtesy of the idea that Jules and Doris Stein had some 45, 50 and 55 years ago to create this Institute.

I would add that the Eye Institute has taken up this challenge in the form of an initiative called the Audacious Goals Initiative. I think that Jules would have been pleased, and would have asked a broad constituency of scientists within vision and beyond vision to think what could be done if we employed the new biology that is coming to us courtesy of the human genome.

All of that sounds very good, but there is a great irony, which is the mountain that Larry Tabak spoke of. This mountain, of formidable size, is the Sequester. The Eye Institute budget last year was down by nearly \$50 million. That has resulted in not funding 27 investigators who last year were receiving research funds from the National Eye Institute. Lacking those \$50 million, we simply cannot fund them this year.

I wish that we could communicate better with the American people to explain to them the cost of not doing this kind of scientific work—the cost in terms of delayed treatments for conditions that lead to blindness, heart disease and cancer, which ultimately contribute to death. That's a rather stark statement, but in fact that is the effect the Sequester is having here on NIH, and on the NEI in specific.

I would like the Eye Institute to be able to continue to work with Brian and RPB, and with other organizations, to both educate the American people and to leverage the precious and scarce resources that we have, so that we can honor the legacy of Jules Stein and move forward with developing treatments and cures.

Back to where this began 45 years ago. I think we have real cause to celebrate all of the advances that have come in the wake of the establishment of the National Eye Institute – advances that, looking here across the room, all of you have participated in.

Thank you again, Brian, Katrina and Bill, and RPB, for honoring us with this bust of Dr. Stein, and for this opportunity to recognize the acceleration in eye research that can be traced to his vision for a National Eye Institute.