Legislative Scorecard Issues

Dr. Collins Cites NEI-Funded Human Gene Therapy Research

On April 28 and May 5, respectively, the Labor, Health and Human Services, and Education (LHHS) Appropriations Committees held hearings on Fiscal Year (FY) 2011 NIH funding, featuring primary witness NIH Director Francis Collins, M.D., Ph.D. Early in his testimony, Dr. Collins played a video entitled “Corey’s story,” which featured a recipient of human gene therapy for Leber Congenital Amaurosis (LCA) navigating a maze unsuccessfully prior to the procedure, then successfully after the procedure. This research, funded by the NEI in conjunction with private funding organization Foundation Fighting Blindness at Children’s Hospital of Philadelphia and featured in a June 2008 AEVR Congressional Briefing, received such prominence at the hearings that NAEVR has written to Dr. Collins thanking him for featuring it.

The April 28 House hearing is memorable as it was Dr. Collins' first appearance as NIH Director (he appeared previously as Director of the National Human Genome Research Institute within NIH), and will likely be Chairman David Obey’s (D-WI) last with NIH since he has announced his retirement. Chairman Obey praised Dr. Collins as being “the right person in the right place at the right time” to lead NIH through the post-American Recovery and Reinvestment Act (ARRA) timeframe and to expedite the translation of basic research into treatments. Dr. Collins stated that NIH has done the best job it could to prepare for possibly-reduced post-ARRA funding, while reiterating his top five priorities—genomics, translational research, global health, research that supports healthcare reform, and efforts to reinvigorate the biomedical research enterprise.

Both Democratic and Republican members praised NIH while noting that a funding increase would be tough (see funding chart). Both sides of the aisle questioned whether the Cures Acceleration Network (CAN), authorized by Congress at $500 million in healthcare reform legislation but not yet appropriated funds, could assist NIH in “crossing the Valley of Death from bench to bedside,” that is, the rapid translation of basic research into treatments. Dr. Collins noted that the Institute and Center (I/C) Directors were to have a retreat the next day to address this issue. While commenting favorably on the great flexibility within the CAN model to alter research directions to address the most promising routes, he cautioned that it is “high risk, high reward” research that is not funded.

At the May 5 Senate hearing, Chairman Tom Harkin (D-IA) lamented the tight budget environment, stating that the Subcommittee will be forced to make “tough decisions...and some of our friends are not going to be very happy with some of the decisions we make.” Senator Harkin also expressed his frustration over how CAN could be funded without taking funding away from I/Cs. Senator Arlen Specter (D-PA), the primary CAN sponsor, committed to finding the $500 million in appropriations to fund it.

Vision Community Testifies at Citizen Witness Hearing

At a May 12 House LHHS Appropriations Subcommittee Citizen Witness hearing, Neil Bressler, M.D. (Wilmer Eye Institute/Johns Hopkins University School of Medicine), who represented the American Academy of Ophthalmology, urged Congress to fund NIH and NEI at $ 35 billion and $794.5 million, respectively, echoing NAEVR’s written testimony filed with the House and Senate on April 8. He reminded Members that May is Healthy Vision Month and that, in 2009, Congress passed H. Res. 366 and S. Res. 209 which recognized the 40th anniversary of the NEI and designated 2010-2020 as The Decade of Vision. He emphasized that the 2.5 percent “less-than-inflationary” NEI increase in the President’s budget proposal was inadequate to handle vision impairment and eye disease challenges.

He added his unique perspectives from his roles as Chair of the Food and Drug Administration’s (FDA) Ophthalmic Devices Panel and as Chair of the Diabetic Retinopathy Clinical Research (DRCR) Network, the NEI-funded collaborative, multi-center network dedicated to facilitating clinical research into diabetic retinopathy, diabetic macular edema, and associated conditions. He cited recently reported results of a DRCR Network comparative effectiveness trial which confirmed that laser treatment for diabetic macular edema, when combined with injections of the FDA-approved drug Lucentis, is more effective than laser treatment alone, the latter of which has been the standard of care for the past 25 years. “Nearly 50 percent of patients who received this new treatment experience substantial visual improvement, and fewer than 5 percent experience substantial vision loss,” said Dr. Bressler. “The investment by Congress to the NIH to make studies such as these possible is an example of the huge successful impact that these funding increases can have on the quality of life and productivity of America.”

Earlier on May 12, the Alliance for Aging Research held a Congressional Briefing to release The Silver Book: Diabetes, a compendium of the latest data about the incidence and economic impact of the disease. It also contains data about the impact of diabetic eye disease, building upon The Silver Book: Vision Loss, released in September 2007, which the Alliance developed with NAEVR.

![Cong. David Obey (D-WI), who chairs both the House Appropriations Committee and LHHS Appropriations Subcommittee, presided over the Citizen Witness hearing at which many witnesses thanked him for his past dedication to biomedical research](image1.png)

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<tr>
<th>FY 2008 Final</th>
<th>FY 2009 Final**</th>
<th>FY 2010 President’s Request</th>
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<tbody>
<tr>
<td>NIH*</td>
<td>$29.38 B</td>
<td>$30.3 B + 3.2%</td>
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<tr>
<td>NEI</td>
<td>$670.7 M</td>
<td>$688.5 M + 2.2%</td>
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* | Net of Transfers/Capital Expenditures |
** | Above ARRA Funding |

Visit the dedicated NIH/NEI and ARRA funding sections of NAEVR’s Web site for full details