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DRRC MEETINGS WITH NIH LEADERSHIP: SYNOPSIS OF DISCUSSIONS

On Tuesday, May 23 2017, representatives of several DRRC member organizations and Powers Law staff met with NIH officials at the NIH campus to discuss federal medical rehabilitation and disability research and the implementation of recently-passed legislation, S. 800, which was incorporated into the 21st Century Cures Act. The DRRC group met with Dr. Diana Bianchi, Director of the National Institute of Child Health and Human Development (NICHD), Dr. Alison Cernich, Director of the National Center for Medical Rehabilitation Research (NCMRR), and Dr. James Anderson, Director of the Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI) within the Office of the Director.

In all three meetings, the DRRC representatives described the history of DRRC efforts with NIH to date and the importance of medical rehabilitation and disability research, using illustrations of existing and emerging research topics. The group also sought feedback and input from the NIH staff on specific NIH research developments as well as the implementation of Section 2040 of the 21st Century Cures Act (PL 114-255) known as the Enhancing the Stature, Visibility and Coordination of Medical Rehabilitation Research at NIH Act of 2016. This summary provides a brief review of the highlights from those meetings. For additional context, please see the associated agenda and attendees documents. In particular, the meeting agenda (attached) served as the basis for the introductory conversation that led to the discussions presented in the summary below.

Key Takeaways for DRRC

1. **Dr. Anderson indicated a willingness to support better awareness of rehabilitation research across the NIH Institutes and Centers and presented several ways to do so directly.** He indicated that a key reason rehabilitation research does not have as high a profile as other types of research at NIH is due to process – that is, better coordination with the NICHD and other institutes and centers pursuing rehabilitation research is needed. In that comment, he reaffirmed DRRC's longstanding understanding of the state of medical rehabilitation research at NIH. Dr. Anderson indicated that he was willing to continue reminding institute directors to be mindful of the field, given that his role is to help coordinate such interactions. He suggested he would be willing to recommend to NIH Director Dr. Francis Collins that NICHD Director Bianchi should present to her fellow institute/center directors about NCMRR and rehabilitation research at one of the periodic institute director meetings.

a. **DRRC should follow up with Dr. Anderson to ensure that he makes this request to Dr. Collins;** additionally DRRC should work with Dr. Bianchi, Dr. Cernich, and NCMRR to assist them with the preparation of such a presentation, as needed.

b. **DRRC should conduct additional follow up visits with other Institute Directors to make them better aware of rehabilitation research.** Dr. Anderson suggested we visit with at least the other top funders of rehabilitation research at NIH, which include the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), and the National Center for Advancing Translational Sciences (NCATS), among others including the bioengineering, aging, cancer institutes. DRRC plans to conduct its next series of NIH visits in the fall.

2. **NCMRR is undertaking a vast research grant portfolio analysis to better understand the extramural rehabilitation research that the NIH funds.** Based on the 2015 research portfolio, which can be found publically available on the web, the Center is categorizing and coding each NIH rehabilitation research grant that they fund extramurally, and will do so with intramural funding in the future. Currently, they have coded 800 of the 13,000 or so grants, which total about $475 million in funding. Dr. Cernich indicated that one goal is to identify trends in research funding, gaps, and areas where new investment can and should occur. This effort will inform future work to revise the NCMRR research plan.

   a. **Definitional Issues:** Dr. Cernich's team began their work before the passage of the 21st Century Cures Act, which included a definition in statute for the term, "medical rehabilitation research." They are instead operating off of a definition that is similar to the one in statute, but is based on search terms and defined categories that the NIH currently uses. Apparently, to change the category or definition is an immense amount of work that would significantly derail any current efforts that NCMRR is undertaking, so they are aiming to finish their analysis on this cohort under the initial definition and then convert to the statutory definition in future analyses.

      i. **Dr. Anderson did not support having a legal definition of "medical rehabilitation research" in law.** He said that "scientists should be able to decide what the definition is and update it as needed." DRRC representatives reminded him that the definition added into statute by the 21st Century Cures Act was developed by a blue ribbon panel of rehabilitation scientists and researchers. Notwithstanding his view, the definition of this term is in statute and NIH will have to implement it in the future.

   b. **Dr. Anderson and his team are supporting the portfolio analysis Dr. Cernich is leading via the NIH Office of Portfolio Analysis.** His division contributes staff and analysis resources. As he put it, he believes this work helps the NIH better understand "the science of science," in other words, how funded scientists collaborate and what the current field is undertaking. He said this work maps networks of researchers on particular topics and is important to help NIH understand the "trajectory" of initiatives, to better fund projects and grants that build upon one another to advance the science forward in a linear fashion. Dr. Anderson indicated he believes that his office can contribute more resources to Dr. Cernich's effort, and will work to do so. In fact, in subsequent email communication with Dr. Cernich, it was noted that Dr.

Anderson already followed up with Dr. Cernich to schedule a meeting to continue discussing how DPCPSI can continue interacting with NCMRR.

   i. **DRRC will follow up with Dr. Anderson to ensure he devotes more resources toward the NCMRR portfolio analysis project.**

3. **Dr. Anderson broadly indicated that his office is looking to develop more metrics to better understand how research is conducted, the outcomes it produces, and ways for it to improve.** For instance, he noted that his team has publicized a metric called the relative scientific ratio, which essentially creates a co-citation network that shows how a particular paper is cited and fits into the network of other related citations. Ultimately, these metrics will help NIH drive researchers toward working together better and in less isolation.
4. **Dr. Cernich described a new RFP for a limb loss registry program that is being co-funded by NCMRR in partnership with the Department of Defense (DoD).** The RFP was announced late on Monday 5/22/17. The NICHD is partnering with the Department of Defense (DoD) on this clinical registry for amputation and prosthetics. The DoD leads efforts to document the etiology, care, and follow-on needs of military members who have incurred an amputation because of traumatic injury but lacks information on those Service members who leave the military health system and seek care in the private sector. Additionally, information from the civilian sector will increase the amount and quality of data available on clinical care pathways, surgical techniques, and prosthetic components to potentially benefit Service members and their beneficiaries in the future.
5. **Funding for various types of grants and programs was broadly discussed.** NICHD is looking at ways to better fund initiatives such as training grants and the Small Business Innovation Research (SBIR) program. The group broadly discussed funding initiatives and priorities at NICHD and NCMRR with Dr. Bianchi. The Director noted that historically, 5-10% of NICHD funding has gone toward training programs, and indicated that will remain the case. IDEA states, translational centers, and the SBIR program were all noted in the conversation, with the NIH staff generally supporting those programs but recognizing that they erode the Institute's ability to fund extramural investigator-initiated grant applications. Dr. Bianchi also mentioned that the Office of Science Reporting and Analysis has played a large role in their ability to track grants and the extramural work done by researchers.

Conclusion

All DRRC representatives agreed that the meetings with NIH were very valuable and that DRRC should continue visiting NIH Institute and Center leaders to promote rehabilitation science.