

MEMORANDUM

To: DRRC Membership

From: Peter Thomas, JD, Principal; Bobby Silverstein, JD, Principal; Peggy Tighe, JD, Principal, and Leif Brierley, MPH, Manager of Government Relations

Date: December 15, 2016

Re: DRRC Membership Update and 2017 Prospectus - Updated

Executive Summary

We write to provide you with an update on the Disability and Rehabilitation Research Coalition (DRRC). As we approach the end of 2016, our first year where numerous organizations have made a financial commitment to support the coalition's efforts, we want to provide a summary of efforts made on behalf of the DRRC and its member organizations over the past twelve months, and to provide you with a forecast of issues that the coalition may engage in over the coming year.

The DRRC's size and strength as a representative coalition of organizations concerned with the state of disability, independent living, and rehabilitation research is readily apparent in its active and productive portfolio of issues. This year was no exception, as the DRRC engaged with policymakers, federal agencies, and the rehabilitation research community to advance its targeted agenda. The DRRC continues to see positive results in several of its initiatives, including:

- The passage of legislation to enhance the stature and visibility of medical rehabilitation research at the NIH;
- The development and release of the NIH's first update to its rehabilitation research plan in 23 years;
- Publication of a government-wide strategic plan for rehabilitation, disability, and independent living research; and,
- Our continued national presence and activity through comment letters, direct agency engagement, and participation in national forums on issues related to disability, independent living, and rehabilitation research.

Summary Recommendation: The DRRC Steering Committee strongly recommends that all DRRC member organizations commit to funding the coalition in 2017 at the same levels as 2016. This memorandum is being distributed now in order to assist member organizations in budget planning for the next calendar year.

2016 Review: Initiatives & Engagements on Behalf of DRRC

Throughout 2016 (and in the latter months of 2015), the DRRC engaged in a number of issues intended to advance rehabilitation, independent living, and disability research on multiple fronts.

The following provides a summary of those initiatives and engagements conducted on behalf of the DRRC and its members.

1) S.800/H.R. 1631, the *Enhancing the Stature and Visibility of Medical Rehabilitation Research at NIH Act*, included as Section 2040 of the recently passed 21st Century Cures Act.

In early December, Congress passed bipartisan legislation to enhance and better coordinate medical rehabilitation research at the National Institutes of Health (NIH) as part of the landmark 21st Century Cures Act. President Barack Obama signed the legislation into law on December 13, 2016. The rehabilitation research legislation, S.800/H.R. 1631, the Enhancing the Stature and Visibility of Medical Rehabilitation Research at the NIH Act, was included in Section 2040 of the Cures Act. Introduced in the House by Congressmen Gregg Harper (R-MS) and James Langevin (D-RI) and in the Senate by Senators Mark Kirk (R-IL) and Michael Bennet (D-CO), the bipartisan, bicameral legislation was fully supported by NIH officials, rehabilitation research organizations, clinical associations and disability and consumer groups. Overall, the legislation builds upon the conclusions and recommendations of an NIH Blue Ribbon Panel on Medical Rehabilitation Research, which issued a comprehensive report in January 2013.

DRRC members and staff led the effort to ensure the passage of S.800/H.R. 1631 by hosting a series of Hill visits with staff representing Members of Congress on the Senate Health, Labor, Pensions, and Education (HELP) committee and the House Committee on Energy and Commerce. Throughout the year, DRRC Steering Committee representatives from the American Academy of Physical Medicine & Rehabilitation, American Occupational Therapy Association, and the American Physical Therapy Association accompanied Powers law firm staff and conducted dozens of targeted Hill visits to advocate on behalf of the DRRC on S.800/H.R. 1631.

Due in part to the significant and targeted efforts of members of the DRRC and its staff, in February, the Senate HELP Committee marked up and passed out of committee the Senate version of the bill, S.800, as part of the initial package of noncontroversial bills included in the Committee's efforts to craft legislation to address NIH and FDA issues (dubbed "21st Century Cures" or "Cures" for short in the House, and the "Innovation Act" in the Senate). DRRC's spring and summer meetings with Senate staffers were focused on obtaining support for the initiative while also gaining insight on how the bill might advance to passage.

In the House, H.R. 1631, the companion legislation to S.800, was also well received. Initially, we sought to enlist as many co-sponsors as possible to evidence the House's support for the legislation so that it might be included in any negotiated deal to merge the House's 21st Century Cures bill with the Senate Innovation Act or be advanced as a stand-alone bill or via amendment. However, in September, we received intelligence that the House Energy & Commerce Committee would be possibly repackaging the entire Cures legislative package as a final push to encourage the Senate, which had not agreed on its complete legislative package, to act to pass the Cures legislation. Galvanized by this information, we and members of the DRRC Steering Committee made significant outreach to all member offices of the House Energy & Commerce committee, contacted our bill champions in both House of Congress, met with key committee staffers, and worked hard to include S.800 legislative text in the final Cures package.

As a result of those efforts, our champions urged Committee staff to include the legislation in the final Cures package, noting that it was a priority for their members. As the final Cures draft bill was unveiled, we were excited to have the language from S.800 included in its entirety in the Cures Act. At a Congressional briefing on Capitol Hill organized by the American Physical Therapy Association and cohosted by members of the Disability and Rehabilitation Research Coalition (DRRC), Congressmen Harper and Langevin celebrated the bill's inclusion in the Cures Act. The Congressional briefing featured remarks by a panel representing patient, researcher, and government perspectives, highlighting not only the bill's passage, but the importance of disability, independent living, and rehabilitation research. The event was widely attended, and capped our successful efforts to advance this important legislation. As we turn to 2017, we look forward to continued involvement in advancing the state of disability, independent living, and rehabilitation research at the NIH.

2) Recommendations Sent to the Presidential Candidates

DRRC drafted and sent a position statement to the 2016 Presidential Candidates, advocating for a strong federal commitment to disability, independent living, and rehabilitation research. The DRRC submitted recommendations for improving the lives of Americans with disabilities by enhancing the federal commitment to disability, independent living, and rehabilitation research. Overall, 29 organizations signed on to the final documents, eclipsing the total of 21 organizations from the 2008 presidential campaign. The identical recommendations were sent to representatives for the Clinton and Trump presidential campaigns. Within those recommendations, the DRRC recommended that the Candidate support the development and implementation of a comprehensive research agenda for disability, independent living, and rehabilitation that will:

- Increase federal funding for disability, independent living, and rehabilitation research;
- Enhance the stature, visibility, and recognition of disability, independent living, and rehabilitation research across the federal agencies responsible for supporting this research;
- Improve the coordination, cooperation, and collaboration among federal agencies in supporting disability and rehabilitation research; and
- Increase support for efficacy research, comparative effectiveness research, health care disparities, research capacity, and knowledge translation pertaining to disability, independent living, and rehabilitation research.

We received responses that key health leaders in each campaign received our submissions and we are prepared to answer any questions they may have. In fact, the key Clinton contact is very familiar with the DRRC and its agenda, while the key Trump staffer was formerly a lobbyist with one of the DRRC steering committee groups and worked directly on S. 800 and H.R. 1631.

3) National Center for Medical Rehabilitation Research (NCMRR) Issues Updated Research Plan

Over the past several years, the DRRC has worked to enhance the stature and visibility of rehabilitation research at the National Institutes of Health (NIH) through advocacy efforts directed at NIH officials and their staff, including interactions with NIH leadership (the Director of NIH and his staff), the Director of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) and his staff, the Director of NCMRR and his/her staff, the Medical

Rehabilitation Coordinating Committee, the National Advisory Board on Medical Rehabilitation Research, and other NIH Institutes and Centers as appropriate.

One particular way in which the DRRC has been engaged with the NIH has been through our efforts to encourage the NCMRR to update its research plan, which they had not done since 1993. Following an announcement in November of last year that they would be updating the research plan, DRRC was given the opportunity to help advise NIH during this process through a series of formal comments, and our attendance and participation at several in-person meetings. We submitted formal comments in December, 2015 and attended the NIH Conference on Rehabilitation Research at the NIH in May 2016, at which one session in particular, hosted by new NCMRR Director Alison Cernich, addressed the development of an NIH Rehabilitation Research Plan. DRRC staff consistently engaged with NCMRR/NIH staff throughout the development process, and ensured that DRRC's concerns and points of view were conveyed.

Following this significant activity, on September 14, 2016, NIH released its "[*Research Plan on Rehabilitation—Moving the Field Forward*](#)." The Plan was developed by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development and the NIH Medical Rehabilitation Coordinating Committee. The original plan developed by NIH, "*Research Plan for the National Center for Medical Rehabilitation Research*," was published in 1993.

The Plan was developed by the NICHD and the NIH Medical Rehabilitation Coordinating Committee, with input from DRRC and other stakeholders. Specifically, the DRRC submitted comments to the NIH on draft versions of the plan on multiple occasions over the past year. Additionally, DRRC arranged for Alison Cernich, the Director of the NCMRR, to join the November 9, 2016 monthly DRRC conference call to discuss the new Research Plan.

4) Rehabilitation Research at NIH: Moving the Field Forward Conference

On May 25 and 26, 2016, the NCMRR, National Institute of Neurological Disorders and Stroke, National Institute on Nursing Research, and the National Institute of Biomedical Imaging and Bioengineering held a conference on rehabilitation research. The intent of the [conference](#) was to:

- Address the full scope of the rehabilitation research portfolio at the NIH;
- Highlight accomplishments and advances that have resulted from NIH-sponsored projects and programs; and
- Provide the scientific community and the public an opportunity to provide input in the development of the recommendations for the NIH Rehabilitation Research Plan.

DRRC staff and multiple DRRC members attended and participated in this significant rehabilitation research conference, which attracted over 500 participants and showcased to senior NIH officials the enthusiasm and productivity of the rehabilitation research community.

5) Submission of Comments on Behalf of DRRC Addressing NIDILRR NPRM

On February 19, 2016, the DRRC submitted comments on the Proposed Rule for the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) (RIN 0985-AA12). The Proposed Rule implemented the Workforce Innovation and Opportunity Act of 2014 (Pub. L. 113–128), which made significant changes to Title II (Research) of the Rehabilitation Act of 1973

(Pub. L. 93-112). It also implemented the transfer of the NIDILRR from the Department of Education to the Department of Health and Human Services (Administration for Community Living).

In our comments, DRRC offered support for several key streamlining and regulatory changes made to NIDILRR regulations and HHS policies, while also voicing our concerns over some aspects of the program. In particular, our comments reflected the following:

“We support:

- (1) The consolidation of the NIDILRR regulations into a single part and alignment of the NIDILRR regulations with the statute and HHS policies.
- (2) The elimination of unnecessary regulatory language that already exists in other documents, such as the application materials or terms and conditions of grant awards.
- (3) Largely retaining appropriate language from the existing Department of Education regulations.

However, given the proposed streamlining of the regulations, we expressed concern that an entity potentially eligible for an award under a NIDILRR program that had little or no experience applying for funding may no longer be able to rely on the regulation to determine whether and how to apply for NIDILRR funding. We recommended that the NIDILRR website be updated to include specific information or hyperlinks to materials that would explain the process for applying for funding so that such an entity could make an informed decision about whether and how to apply for NIDILRR funding.”

6) Multiple Comments on Interagency Committee on Disability Research (ICDR) Government-Wide Strategic Plan Submitted and Plan Development Monitored

DRRC provided a response to the materials shared with individuals participating in the ICDR Strategic Plan—Stakeholder Input Webinars held on November 4 and 5, 2015. By way of background, the Workforce Innovation and Opportunity Act (WIOA) (Public Law 113-128) required the ICDR to develop a comprehensive government-wide strategic plan for disability, independent living, and rehabilitation research. The plan was required to include:

- A description of measureable goals and objectives with agency resources, timetables and responsible persons
- Research priorities and recommendations
- Development and maintenance of searchable government wide inventory of research
- Guiding principles for conducting and administering research across agencies
- Summary of underemphasized and duplicative areas of research

The DRRC provided comments in both November, 2015 and March, 2016, highlighting several key issues and concerns that we hoped the ICDR Strategic Plan would address. In particular, the DRRC comments highlighted our concerns that the materials presented at the webinars and the processes

used to secure stakeholder input did not adequately effectuate congressional intent. To that effect, we submitted detailed questions calling upon the ICDR to consider more specifically many aspects of the law that they were responding to, particularly in the research domain of “health and function” research.

The DRRC also submitted in its comments a request to meet with ICDR leadership to discuss how best to proceed in effectuating congressional intent and to ensure the development and implementation of a comprehensive, government-wide strategic plan for disability, independent living, and rehabilitation research that would contribute to the improvement of the employment, health and function, and community participation of people with disabilities.

7) Call for Rehab Researchers to Participate in Study Sections

Most recently, the DRRC has established its process for gaining participation from disability, independent living, and rehabilitation researchers in the field in study sections at the NIH and other federal agencies. The DRRC Alert and call for action was issued in October, 2016. The anticipated, resulting database will allow the research, consumer, and clinical communities to better engage with the federal agencies on grant reviews and study sections that determine which projects receive federal funding in the area of rehabilitation, disability, and independent living. The request also applies to clinicians who have a research interest and consumers who would be good candidates to represent the patient perspective in research grant reviews.

8) Managing the DRRC and Engaging Its Membership

Powers staff have continued managing the DRRC, including planning and facilitating monthly calls of DRRC members to provide information and resources; seeking input and approval on draft advocacy documents, letters to policymakers, and other advocacy efforts; and focusing special attention on the continued development of active consumer/disability engagement in research policy issues. Powers staff invest significant time and resources into addressing the needs and issues of this coalition. The full DRRC membership convenes by phone each month.

PROSPECTUS: 2017

As we approach the end of 2016 and throughout 2017, the DRRC anticipates continued engagement on a number of fronts related to disability, independent living, and rehabilitation research. 2017 will feature not only a new President, Administration, and Congress, but an opportunity to highlight the importance of disability, independent living, and rehabilitation research before a new audience. Several continuing issues provide opportunities for the DRRC to have an active hand in the shaping of disability, independent living, and rehabilitation research policy and activity at the national level. Those include:

- Significant work to maintain our positive engagement with the NIH, the National Center for Medical Rehabilitation Research (NCMRR), and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), especially given the passage of S.800, to ensure that the legislation is properly implemented and coordinated.
- Outreach to other important federal rehabilitation research centers, including the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), the

Department of Veterans Affairs (VA), the Department of Defense (DoD), the Centers for Disease Control and Prevention (CDC), and others, to increase federal coordination of disability, independent living, and rehabilitation research.

- Continued engagement with the ICDR on its Strategic Plan development to ensure that the ICDR fulfills its congressional mandate to develop a comprehensive government-wide strategic plan for disability, independent living, and rehabilitation research.
- Following up on our submission of Recommendations to the Presidential Candidates, the DRRC has a responsibility to work with the new President and his/her administration to ensure that the President acts upon our comprehensive recommendations. Our engagement with the new Administration will be important to advancing these important policy goals.

As your DRRC staff, we look forward to continuing to serve this important coalition in the new year, and wish to express our gratitude for your involvement in this critical work to advance the field of disability, independent living, and rehabilitation research policy and activity at the national level.

Sincerely,

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