

**WRITTEN TESTIMONY OF ROBIN L. RUSCONI, JD**  
**CHAIR, BOARD OF DIRECTORS**  
**NATIONAL ASSOCIATION OF VETERANS' RESEARCH AND EDUCATION**  
**FOUNDATIONS (NAVREF)**

**PREPARED FOR THE HOUSE COMMITTEE ON VETERANS AFFAIRS**  
**SUBCOMMITTEE ON OVERSIGHT AND INVESTIGATIONS**  
**AND**  
**SUBCOMMITTEE ON HEALTH**

**MAY 17, 2018**

Chairmen Bergman and Wenstrup, Ranking Members Kuster and Brownley, distinguished members of the subcommittees, thank you for holding this important hearing. VA Research is an essential but underpublicized element of the VA health care system. It has a distinguished history of discovery and innovation that has benefitted Veterans and the nation for over 90 years. The congressionally authorized VA-affiliated nonprofit corporations are proud to support and augment VA research. I believe the nonprofits are making critical contributions to the success of VA research.

My name is Robin Rusconi. Since 2014 I have been the Executive Director of the VA-affiliated nonprofit corporation located in Kansas City, Missouri, the Midwest Biomedical Research Foundation. MBRF supports research and education activities at VA medical centers in Kansas City, Missouri, and Leavenworth, Topeka, and Wichita, Kansas. I am currently the Chair of the Board of Directors for the National Association of Veterans' Research and Education Foundations, known as NAVREF. Since leaving the active practice of law in 1997, I have been engaged in the nonprofit sector and in research administration, including 13 years at Children's Mercy Hospital as a development officer and then Director of Medical Research Administration. As a child of two World War II Veterans, I am proud to be supporting the VA research program and helping improve the lives of Veterans.

As the national association, NAVREF's mission is simple—we exist to advance the success of the VA-affiliated nonprofit research and education corporations (NPCs). The NAVREF Board of Directors is experienced and knowledgeable about research administration, nonprofit leadership, and supporting Veterans. The Board is comprised of seven NPC executive directors elected by the membership, four VA employees elected by the membership consisting of a VA Medical Center Director, Chief of Staff, Associate Chief of Staff for Research and Development, and Associate Chief of Staff for Education, and two community members appointed by the board. I am here today on behalf of the NAVREF Board and our membership to tell you about the great work of these nonprofits, our potential for greater contributions, and the progress made since last year's hearing.

We are pleased that the House Veterans Affairs Committee recognizes the importance of the nonprofit corporations to the VA research enterprise. The NPCs were authorized by Congress under 38 USC §§7361-7366 to provide flexible funding mechanisms for the conduct of research and education at VA facilities nationwide. Over the last four years alone, the NPCs have administered over \$1 billion in support of research activities at VA medical centers.

As flexible funding mechanisms, the NPCs offer a multitude of services and benefits to VA research and education programs. This includes numerous benefits to their local VA medical centers and the Veterans they serve, including the following 10 common support services:

- Renovate and upgrade VA research infrastructure
- Provide funds, staffing, and training support to VA Research and Institutional Review Boards

- Pay for expenses related to recruitment of research investigators to the VA system
- Fund seed grants to new investigators to aid them in establishing their VA research careers
- Fund training of VA personnel on a wide variety of topics
- Underwrite bridge funding for VA investigators who are between research grant awards
- Support travel and registration fees for VA personnel to attend scientific conferences
- Procure personnel, equipment, and supplies for VA-approved research or education projects
- Host local and national educational conferences for VA personnel
- Act as fiscal agent for philanthropic and other available research funds

As seen from this listing, the nonprofit corporations are making daily contributions to VA research and education programs across the country. Importantly, the NPCs focus all their resources in support of VA research and education activities. Even the overhead rates applied by the NPCs (which, on average, are 50% less than those of universities), ultimately accrue to the benefit of the supported VA medical center in the form of personnel, equipment, training, and supplies.

NAVREF and its members are excited to support Dr. Ramoni's three strategic priorities for VA research – to provide greater access to clinical trials for Veterans, to make VA data a national resource, and to achieve substantial real-world impact.

One recent example of NAVREF's support of VA research priorities is an event we organized last month. On April 12<sup>th</sup> in Arlington, Virginia, NAVREF hosted over 60 leaders representing VA, the pharmaceutical industry, patient advocacy groups, and the NPCs to pursue a common goal: enhancing Veteran access to clinical trials. NAVREF coordinated the day-long "Stakeholder Summit" to kick-off Dr. Ramoni's two-year effort to establish a dedicated process by which industry sponsored clinical trials can be initiated and conducted efficiently within VA. Enhancing the ability of VA medical centers to work with the pharmaceutical industry will increase the study of conditions prevalent among the Veteran population. In support of this critical initiative, NAVREF is providing Dr. Ramoni a program coordinator to oversee and coordinate the complex effort.

Another example of NAVREF's commitment to support VA research is our involvement on the executive committee for Friends of VA Medical Care and Health Research, known as FOVA. FOVA is a diverse coalition representing national academic, medical, and scientific societies; voluntary health and patient advocacy groups; and veteran-focused associations. Among its many activities, FOVA members regularly brief members of Congress on the funding needs of health care and research at the VA, raise awareness of VA's medical care and research programs, and host special events that highlight VA research successes. For FY2019, FOVA recommends \$823 million for VA research and \$225 million for VA research infrastructure.

While NAVREF is proud of all the NPCs have accomplished since they were first authorized by Congress in 1988, we feel they have the potential to make even greater contributions. In June

2017, the House Veterans Affairs Oversight & Investigations Subcommittee held a hearing about VA research that included testimony from NAVREF. NAVREF offered the following three specific recommendations:

1. VA should establish clear guidelines for the administration of extramural research activities that offer the NPC right of first refusal for all research efforts where the majority of this work occurs physically within the VA. Included in these guidelines should be a common practice for vetting conflicts of interest and ensuring those involved in the decision-making process are not conflicted.
2. VA should review the appropriate level of oversight required to ensure the nonprofit corporations are operating appropriately and effectively while retaining their independence as nonprofit entities legislated to be flexible mechanisms outside of the Federal bureaucracy.
3. The National Institutes of Health (NIH) should modify its Grants Policy Statement to allow our NPCs to pay VA clinicians as Principal Investigators on the Institutes' research grants for their off tour of duty effort.

I'd like to update you on the progress made on these recommendations.

First, at last year's hearing, we were heartened to hear that the Office of Research and Development would engage an outside consultant/contractor to assess the need for VA to establish and enforce clear guidelines for administering federal awards. By Congressional intent in the authorizing statute, NPC's have the ability to administer funds from other federal agencies. Unfortunately, that contract did not get awarded until the next fiscal year and outreach to the nonprofits did not get started until this calendar year. We are frustrated that the process has moved so slowly and we are concerned that the perspective of the nonprofit corporations is not being fully investigated and appreciated. It is also concerning that there are still many instances where the majority of the research effort on a federal award is occurring at the VA, but the award is being administered by the academic affiliate instead of at an NPC that is willing to and capable of administering the award.

This practice contradicts VHA Directive 1200.02 "Research Business Operations" which states, "Extramural funds are funds other than those specifically appropriated for VA research by Congress. These funds may be provided by other Federal agencies, state or local government agencies, non-profit corporations or foundations, other charitable organizations, corporations and other private sector business entities, or an individual contributor. **Such funds are to be administered through the VA Nonprofit Research and Education Corporation (NPC) or through the General Post Fund when possible.**" (Emphasis added by me.)

This directive designates the NPC as the administrator for extramural funds including Federal awards. NAVREF's recommendation for right of first refusal would allow the NPC Board (and

not the investigator) to determine if the NPC is best suited to administer the funds or if they should be administered elsewhere.

Second, the VA's Non-Profit Oversight Board (NPOB) took several positive steps last October regarding the oversight reviews being conducted by the Non-Profit Program Office (NPPO). The NPOB created a clear appeals process and established an anonymous survey tool to receive feedback. The NPOB also directed that oversight review out-briefs not be limited to the medical center director or statutory board members. All NPC board members and the NPC executive director are now being invited to attend these out-briefs. Additionally, the Director of Operations at VA's Office of Research & Development also attends all of the NPPO out-briefs by conference call. What has not yet been clarified for NAVREF is the approved scope of NPPO reviews. VA undertook an internal review of the scope of oversight reviews, but has only reported back that the current scope of reviews has been deemed appropriate under OMB A-123. It would be helpful if VA could share the details of the review—how the current scope was defined, what criteria were used, and how the assessment was performed. Without this information, our members—all independent, non-governmental 501(c)(3) corporations--remain confused about what items are subject to VA review and what may be out-of-scope.

Third, the NIH Grants Policy Statement (GPS) remains unchanged in regard to the ability of an NPC to pay VA clinicians from NIH awards. NAVREF intends to meet with appropriate NIH leadership in the coming weeks to address our concerns with the GPS language and its negative impact on the NPCs.

In summary, we were very pleased with the commitments made at last year's hearing, and look forward to continued progress. We have, however, been disappointed with the pace of implementation over the last ten months. Our most significant concern continues to be the administration of federal awards when the majority of effort is performed at the VA medical center. We would like to see this practice clarified and enforced to be consistent with the congressional intent for the NPCs.

Thank you again for your attention to these matters. We greatly appreciate your continuing support of the VA research program and your support of the VA-affiliated nonprofit corporations. We share a common vision of a nation in which Veterans receive the finest care based on innovative research and education. We look forward to working with you to achieve this vision.