



HIPAA Privacy Rule for Research- Nonprofits

What are VA Nonprofit Research and Education Corporations (NPCs)?

In 1988, Congress authorized VA medical centers to establish private, state-chartered, nonprofit entities to facilitate VA research and education. NPCs may administer contributions from individuals, private sector companies, other nonprofits and voluntary health organizations as well as non-VA public agencies, such as the NIH, CDC and DoD. Officers, directors and employees are subject to all relevant state and federal statutes and regulations regarding the operations of NPCs as well as federal regulations pertaining to conflicts of interest. In addition, NPCs are subject to VA oversight and regulation.

A few facts:

- Currently, there are 87 active VA-affiliated nonprofit corporations.
- In FY '02, they administered 5,082 projects and had collective revenues of \$185 million.
- Nongovernmental revenues (e.g., pharmaceutical studies) were \$116 million (63%).
- Total expenditures were \$174 million, mostly for salaries of research personnel, but also for research equipment, supplies and research related travel, all in support of VA's research and training missions.
- Education and training benefiting VA staff and patients is a small but growing feature of the NPCs, representing 1.5% of revenues and 1% of expenditures

Who is responsible?

The board of directors is held responsible for all NPC activities.

Who serves on the board?

By statute, the Medical Center Director, Chief of Staff and ACOSs/R and E must serve on the board along with two individuals who are not federal employees, but are familiar with issues involving to research or education. At the discretion of the board, other members may be added to this statutory minimum.

What are the board members' basic responsibilities?

State laws codify the fundamental responsibilities of duty, care and loyalty. Many states are

now adapting the Sarbanes-Oxley Act to require more nonprofit board accountability. Generally, the NPC board of directors should:

- Ensure the furtherance of the VA research mission
- Select and monitor the performance of the executive director
- Monitor and evaluate the financial activity of the NPC
- Ensure legal and ethical integrity of NPC and maintain accountability
- Ensure effective long-term and short-term organizational planning
- Determine, monitor and strengthen the NPC's programs and services

What is NAVREF?

The National Association of Veterans' Research and Education Foundations (NAVREF) is a membership organization of the VA-NPCs. NAVREF's primary mission is to promote high quality management and communication among the VA-NPCs. It conducts two conferences a year on NPC operations, focusing on the unique needs of the NPCs, maintains a web site that contains a wealth of information and supports an office that is an ongoing resource for information. The executive director is Barbara West (bwest@navref.org).

What is the VA Office of Research and Development's (ORD) role in regard to the NPCs?

The VA Non-Profit Program Office was established in early 2003 within the Financial Division of ORD to provide centralized oversight and guidance to ensure compliance with applicable regulations affecting the operation and financial management of VA-NPCs. The program manager is Nancy Maher, PhD (nancy.maher@hq.med.va.gov). One of the first major initiatives of this office, in collaboration with NAVREF, will be to develop and implement a 1-day training module for all NPC board of directors. This training will focus on the roles and responsibilities of board members as well as conflict of interest issues, and financial oversight. This training is scheduled to begin in the Fall of 2003.