



NAVREF

NATIONAL ASSOCIATION OF VETERANS' RESEARCH AND EDUCATION FOUNDATIONS

ENVISIONING A NATION IN WHICH VETERANS
RECEIVE THE FINEST CARE BASED ON INNOVATIVE
RESEARCH AND EDUCATION

ANNUAL REPORT 2019



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A Message from the CEO

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Dear Colleagues:

After the fanfare of our 25th Anniversary year, NAVREF kept its foot on the gas for a fast-paced, productive 2018-19 year. As I reflect on the last 12 months, I am most proud of our strong collaborations with the DoD, the NIH, and VA to improve the lives of veterans.

After working for almost 6 months with the DoD's US Army Medical Research Acquisition Activity, NAVREF issued guidance to NPCs in October 2018 detailing when and how to seek reimbursement for VA salaries on DoD research awards. Similarly, NAVREF has been working closely over the last 8 months with NIH's Office of Policy for Extramural Research Administration (OPERA) to create similar guidance about reimbursing VA salaries and benefits that is consistent with federal regulations and NIH policy. We hope to finalize this guidance in the next few weeks.

Our collaborations with VA have been strong across many fronts, but most impactfully with the Access to Clinical Trials for Veterans initiative that has been making steady, powerful progress for the last 15 months. Ultimately, we envision VAMCs and NPCs becoming industry's partners of choice for multi-site clinical studies, which would bring the benefits of more clinical trial opportunities to veterans at VA medical centers.

I am also proud of NAVREF's rapid response to dismaying news about changes to the management of Interagency Agreement funds at the NPCs. When it was determined that only new legislation could fix the problem, NAVREF jumped into action to work with the House Veterans' Affairs Committee leading to the introduction of H.R. 1947, which was unanimously approved in committee and then approved by the full House on May 21st! We are optimistic that the Senate will take this bill across the goal line before the end of FY2019, effectively restoring another tool in the NPCs' toolbox of flexible funding mechanisms.

None of this work could have been accomplished without the support of key federal leaders such as Dr. Carolyn Clancy, Dr. Rachel Ramoni, and Dr. Grant Huang from VA, Ms. Michelle Bulls from NIH, or Mr. Brian Martin from USAMRAA. Equally important are the contributions of our partnering nonprofits who share our dedication to veterans—most prominently Cohen Veterans Bioscience, the Association of VA Hematology & Oncology, Veterans Against Alzheimer's, and the Longevity Foundation. Thank you all for a great year!

Sincerely,



Mr. Richard Starrs
NAVREF CEO
US Army Colonel (retired)

NAVREF STAFF



We're a small organization with a tight-knit team! In addition to our CEO, Colonel (retired) Rick Starrs, the organization is supported by two full-time staff members: Ms. Krissa Caroff, Clinical Trials Facilitator, and Mr. Hawk Tran, Operations Officer. Their hard work and dedication to our meaningful vision directly supports the success of our members.

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The 2018-2019 membership year was a fun and challenging one filled with new opportunities. This annual report captures some of the headline activities from each of our program areas, but the cornerstone of our daily efforts is customer-service...we exist purely to support the needs of our member NPCs as they strive to improve the lives of veterans.



Member Services and Communications

- NAVREF's member assistance and communication continue to receive the highest satisfaction scores, maintaining increases of **30%** since 2016.
- Satisfaction with the Newsletter increased for the 3rd consecutive year, as distribution and use continue to grow
- Mr. Starrs **visited 14 NPCs** this year, including 7 repeat visits and 7 new visits, for a **total of 41 unique NPC visits** in his first 40 months as CEO, gaining valuable insights into NPC operations and local challenges.



Education

- NAVREF's 26th Annual Conference set attendance records with the novel addition of the ACOS-R community; we look forward to sharing our conference with them again in 2020 back in DC
- NAVREF collaborated with the Society for Research Administrators International (SRAI) to deliver one highly-rated grants management workshop in 2018-19 and plan a second for July 2019.
- For the 2nd year, NAVREF collaborated with ACRP to offer ACRP's eLearning Program to all NPC-affiliated personnel (both NPC and VA personnel are eligible.)
- The NAVREF monthly webinar series included 15 offerings over the last 12 months with average participation of more than 28 members per session.



Program Development

- NAVREF coordinated and disseminated 52 clinical study opportunities over the last 12 months!
- NAVREF partnered with three non-profits to provide financial support for the ACT for Veterans initiative.
- NAVREF partnered with the Association of VA Hematology and Oncology (AVAHO) to provide staff support and expertise related to oncology clinical trials for Veterans.
- By building collaborative partnerships, NAVREF grew conference sponsorship revenue in 2018, leading to reduced registration fees for the 2019 Conference.

Top Highlights

- **ACT for Veterans** – this initiative formally kicked-off in April 2018 with a NAVREF-hosted "Stakeholder Summit." Our effort to enhance access to clinical trials for veterans at VA medical centers has made great strides over its first 16 months and has garnered strong support from VA stakeholders and the clinical trials industry. We are excited to see the first pilot efforts in Summer 2019 and ultimately want VA to become industry's partner of choice for groundbreaking clinical studies.
- **PACERS** – this initiative is focused on enhancing the administration of extramural awards through greater collaboration at local sites between the VAMC, NPC, and academic affiliate. While every site is different, PACERS will provide a menu of successful strategies and best practices for sites to consider.
- **Training Workshops** – over the last 12 months NAVREF conducted three well-received 2-day workshops—one focused on post-award grants management and two offerings of "NPC Essentials" to address the foundational elements of NPC management.

NAVREF 26TH ANNUAL CONFERENCE SPEAKER HIGHLIGHTS



Left: Rep. Neal Dunn (R-FL), House Vet. Affairs Committee



Above: Dr. Carolyn Clancy, Deputy Undersecretary for Health Discovery, Education and Affiliate Networks at Veterans Health Administration (VHA) Left: Dr. Rachel Ramoni, Chief Research and Development Officer, VHA, ORD



Program Highlights from 2018 - 2019



Member Benefits

- NAVREF provides members access to an extensive library of information through a website focused on NPC regulations, policies, guidance documents, and lessons learned.
- NAVREF offers Best Practice Consultations free to members--these BPCs provide thorough review of policies and practices by seasoned, experienced peers in a collaborative, supportive environment.



Advocacy and Lobbying

- NAVREF is leading "Friends of the VA" lobbying efforts, which last year helped increase the 2019 VA research appropriation by \$57M.
- NAVREF inspired and successfully guided H.R. 1947 through the House of Representatives and is working closely with Senate staffers to make this bill the law so that NPCs can once again handle Interagency Agreement funds without regard to expiration dates.
- Following in-depth discussions with the Department of Defense, NAVREF disseminated helpful guidelines for the administration of DoD awards and payment of federal salaries.
- NAVREF has been actively engaged with NIH leaders to establish clear guidance on the reimbursement/payment of VA salaries and benefits when work is performed in support of NIH awards.
- NAVREF actively participates in VA's PACERS initiative to improve collaboration among VAMCs, NPCs, and Academic Affiliates in the administration of extramural research.



Picture of the 2018 NAVREF awards winners. From left to right: Ms. Mary Thornton, Mr. Kevin Hull, and Ms. Rebecca Rosales



NAVREF members posing within the Capitol Hill Visitor Center during NAVREF's 2018 Take the Hill Day in Washington, DC.

In Appreciation

NAVREF is thankful for the generous contributions of time, energy, and passion from numerous individuals and organizations. At the top, the NAVREF Board of Directors is an extremely dedicated group of leaders with demanding schedules who still make the time to support research and education programs for Veterans. In 2018-19, as in previous years, leaders from across the nonprofit corporations volunteered to participate as NAVREF committee members, work group members, presenters, mentors, and subject-matter experts. Our sense of community and camaraderie is what makes NAVREF so special. Thank you for your selflessness and dedication to our mission--you keep me inspired!

Program Satisfaction



How are we doing?

Thank you for completing our survey and letting us know that we are going in the right direction!

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ACT Initiative

In December 2017, VA's Office of Research and Development (ORD) and NAVREF embarked on a new effort to increase veterans' access to clinical trials. The initiative kicked off with a Stakeholder Summit in April 2018 which brought together representatives from industry, VA Central Office, VA medical centers, patient advocacy groups, and the NPCs to participate in facilitated discussions centered around study start up. Since that initial meeting, 5 top priorities (establishing a single point of contact (SPOC) model; establishing VA assets and capabilities; establishing information VA needs from industry; creating a process map related to study start up; and developing resources needed to adhere the Single IRB mandate coming in January 2020) were identified, and workgroups were commissioned to address these priorities.



ACT for Veterans Initiative

ACCESS TO CLINICAL TRIALS FOR VETERANS

In February 2019, a Workgroup Summit was held in Washington DC which allowed the five workgroups to come together, present their respective products, and give/receive feedback on those products. Key results and actions taken since that meeting include:

- Drafting of responsibilities and standard operating procedures for the Single Point of Contact (SPOC) model.
- Development of tools such as a site profile template and a catalog of VA clinical assets
- A list of the critical information needed from industry to facilitate discussions regarding a new trial
- Obtaining approval for single VA sign-off of Non-Disclosure Agreements (NDAs) . An implementation process is under development.
- Development of a centralized budgeting framework and lead site capabilities and responsibilities.
- Initiation of a multisite IRB network.
- Exploring opportunities for future collaboration with commercial IRBs, and obtaining resources to address staffing needs.

ACT for Veterans anticipates that pilot activities will commence in Summer 2019.



2018 - 2019 Donor Recognitions



NAVREF Star | \$20,000 and Up

Association of VA Hematology and Oncology
Cohen Veterans Bioscience
The Lungevity Foundation
Veterans Against Alzheimer's



NAVREF Champion | \$6000 to \$19999

We still need champions!



NAVREF Hero | \$1000 to \$5999

Liam Donohue
Robert Forrester
Jeff Jakubiak
Mary Sano, PhD



NAVREF Ally | Up to \$999

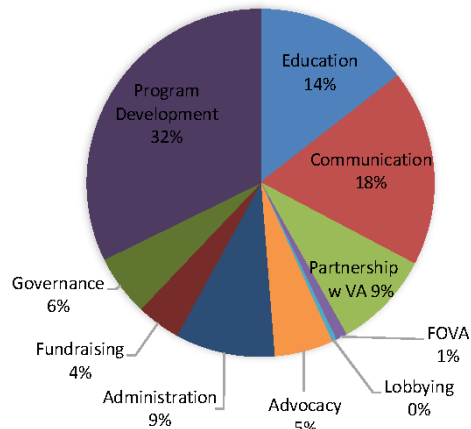
Marti Baumert • Jennifer Brunner • Shelley Cobb • Danielle Fleumer • Scott Gruber • Ron Hakes • Kevin Hull • Jeffrey Jamer • Cheryl James • Kent Kester • B. James McCallum • Jeffrey Moore • Kelly Page • Ashley Phillipps • Mike Quinata • Cindy Reutzel • Robin Rusconi • Paul Russo • Steve Scebelo • Edward Schoder

*Thank
You!*

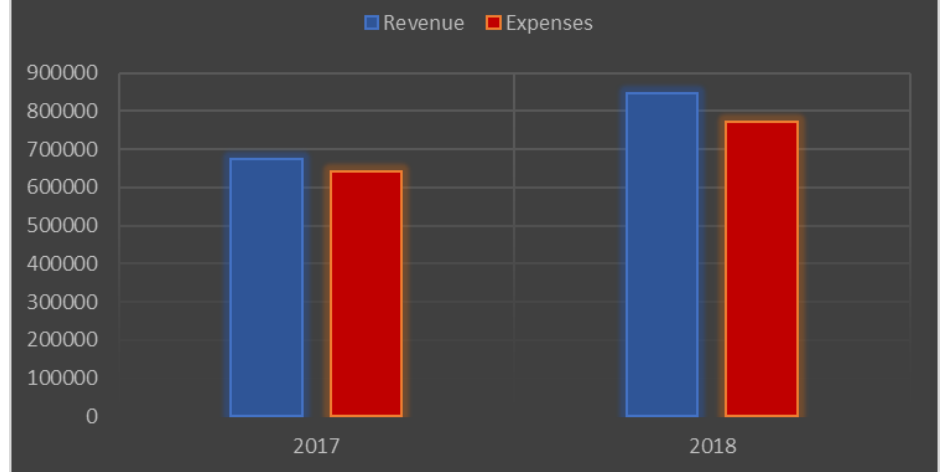
NAVREF is truly appreciative of our supporters as their generous contributions have helped strengthen our community to provide cutting edge healthcare and improve the quality of life for so many veterans.

NAVREF Financials

**PROGRAM ALLOCATIONS
FY2018**



Revenue vs. Expenses



NAVREF has continued to manage resources efficiently, such that annual revenues exceed expenditures year-in and year-out, building a strong reserve. In FY2019, NAVREF has begun spending down the reserve by implementing membership dues reductions, slashing conference registration fees, and offering more educational opportunities. We are pursuing a fundraising plan in 2019-20 to further enhance our support of the NPCs and profoundly impact veterans research & education programs.

On the Horizon For 2019-2020

The upcoming membership year will kick-off with a bang as we introduce Annual Dues Reductions for the first time!! We will use reserve funds to offset the loss in dues revenue this year, but ultimately, we intend to generate other revenue streams so that these temporary reductions can be made permanent.

Additionally, we will use our reserves and increased conference sponsorship revenue to slash conference registration fees by 50%. Registration for the 2019 Annual Conference will be \$430 for all member NPCs. This year's conference — our 27th annual — is already shaping up to be a memorable event with high-profile speakers and impactful learning sessions.

In July 2019, NAVREF will offer a new NPC Grants Management Workshop focused on pre-award requirements & activities. These Workshops are executed in collaboration with the Society of Research Administrators International (SRAI) and would typically cost over \$850/attendee, but are provided free of charge to NAVREF members.

In August 2019, NAVREF will enter its third year of a contract with the Association of Clinical Research Professionals (ACRP) that provides members and affiliates with free e-Learning opportunities through the nation's most trusted provider of education and training for clinical research professionals.

NAVREF will begin pursuing a more robust Fundraising Strategy in FY2019 that we expect will lead to new sources of revenue and deliver increased value to the membership, helping to supplement or offset member dues.