

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

# ANNUAL REPORT 2020



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# A Message from the CEO

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ACOS-R

#### Dear Colleagues:

Three-quarters into our 2019-2020 membership year, I was excited about the progress we had been making and the trajectory we were on. Our ACT for Veterans initiative was producing tangible results, our foray into fundraising was picking up momentum, we'd received our first "Champions Level" sponsorship, and our joint planning for the



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

2020 annual conference in DC with the ACOS-R community was shaping up brilliantly. Then COVID-19 hit our shores and the world fundamentally changed. We were all forced to adjust our lives and re-assess our priorities. In that re-assessment, I returned to what brought me to NAVREF in the first place. Community. Undergirding all our initiatives and accomplishments—as advocates, policymakers, communicators, and change agents—is the spirit of collaboration and cooperation among like-minded individuals collectively pursuing a higher goal. Since March 24th, NAVREF has hosted and moderated 50 hours of video discussion groups with NPC leaders for the purpose of building connections and maintaining community. We provide updates, ask questions, share stories, and assist each other in ways large and small. NAVREF exists to support our community of nonprofits, to represent your needs, and to be your voice, as we all strive to improve the lives of veterans through research and education.

The 2020-2021 membership year will surely be a challenging one for all of us. I firmly believe that our ethos of community and togetherness will enable us to overcome the challenges and accomplish our missions while leaning on each other and supporting each other. I am proud to be part of this community and thrilled that NAVREF can serve as the connecting tissue that binds us together.

NAVREF had many accomplishments in 2019-2020 that you can read about on these pages, but our most valuable contribution is supporting and stoking that spirit of community that inspires all of us to grow, achieve, and succeed.

Sincerely,



#### **NAVREF STAFF**

We're a small organization with a far-reaching impact! In addition to our CEO, Colonel (retired) Rick Starrs, the organization is staffed by two full-time professionals: Ms. Krissa Caroff, Clinical Trials Facilitator, and Mr. Hawk Tran, Operations Officer. Their commitment to service and dedication to our veteran-focused mission is reflected in everything they do.



# NAVREF ANNUAL REPORT 2020

The 2019-2020 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 to support the needs of our member NPCs as they strive to improve the lives of veterans.



# **Member Services**

- Overall Member Satisfaction increased for the 4th consecutive year.
- Dues were reduced across the board for all members.
- NAVREF immediately established a repository of COVD-19 resources, fostered weekly video discussion groups, and issued regular, transparent updates in an effort to keep everyone together and engaged as a community.



## Education

- NAVREF's 27th Annual Conference was again the signature educational event of the year bringing together leaders from 62 NPCs across the country.
- NAVREF collaborated with the Society for Research Administrators
   International (SRAI) to deliver two popular grants management workshops in 2019-20.
- For the 3rd 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 13 offerings over the last 12 months with average participation of more than 40 members per session.



# **Program Development**

- NAVREF coordinated and disseminated 53 clinical study opportunities over the last 12 months
- NAVREF partnered with the Association of VA Hematology and Oncology (AVAHO) and Cohen Veterans Bioscience to provide financial support for the ACT for Veterans initiative.
- By building collaborative partnerships, NAVREF increased conference sponsorship revenue in 2019, leading to half-priced registration fees for the 2019 Conference.

# Top Highlights

- COVID-19 Response The worldwide pandemic changed life for everyone, but I am extremely proud of the way the NPC community rallied together to support each other and continue the missions as best as possible. NAVREF immediately established a repository of COVD-19 resources, fostered weekly video discussion groups, and issued regular, transparent updates in an effort to keep everyone together and engaged as a community.
- ACT for Veterans Successes! With the urging and partnership of NAVREF, VA took significant strides to enhance access to clinical trials including:
  - Introduced new Confidential Disclosure Agreement approval process that slashes turnaround times.
  - Changed policy to allow use of commercial Institutional Review Boards
  - Established the Partnered Research Program within ORD to serve as the single point of contact for industrysponsored trials and to institutionalize the recommendations of the ACT for Veterans initiative.
- Congressional Awards Breakfast On October 24th, 2019, on Capitol Hill NAVREF honored Senator Jon Tester (D-MT), Rep Phil Roe (R-TN), and Rep Julia Brownley (D-CA) as "Champions of Veterans Health" for their dogged support of Veterans, VA research, and the NPCs. The well-attended event launched NAVREF's Accelerator Fund campaign to bring increased attention and resources to the ACT for Veterans initiative.

# THANK YOU TO OUR 2019 CONFERENCE SPONSORS

Janssen, Boehringer Ingelheim, Brain Sentinel, Assurance Dimensions, Candel Therapeutics, RCM&D, Tonix Pharmaceuticals, Express Scripts, Greenphire, PhRMA, Lincoln Financial

# Program Highlights from 2019 - 2020



# NAVREF in the News

- NAVREF highlighted in Applied Clinical Trials article titled "VA Gets Real on Reform" (9-1-19)
- NAVREF published an Op-Ed piece in *The Washington Times* titled "How to Fix Veterans' Access to Life-saving Therapies" (10-29-19)
- NAVREF featured in Clinical Research News "NAVREF launched initiative looks to bring veterans access to clinical trials" (12-17-19)
- NAVREF profiled in BIO Blog titled "How to improve veterans' access to clinical trials" (12-19-19)
- NAVREF published in Combat & Casualty Care titled "Advancing Health through Enhanced Access" (5-1-20)





## Advocacy and Lobbying

- NAVREF published definitive guidance on the reimbursement/payment of VA salaries and benefits when work is performed in support of NIH awards.
- NAVREF led the "Friends of the VA" lobbying efforts, which last year helped increase the 2020 VA research appropriation by \$21M over the President's Budget Request.
- NAVREF honored Senator Jon Tester (D-MT), Rep Phil Roe (R-TN), and Rep Julia
  Brownley (D-CA) on October 24th as "Champions of Veterans Health" for their dogged
  support of Veterans, VA research, and the NPCs. The Capitol Hill event stimulated
  increased attention and resources to the ACT for Veterans initiative.



Senator Jon Tester and Rick Starrs at the October 2019 Champions of Veterans Health breakfast event.

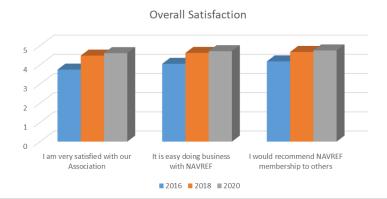
# In Appreciation

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. We added three new Directors in 2020—Peggy Bradley, Michele Packard-Milam, and the Honorable Matt Collier—who will add terrific value and expertise. We welcomed dedicated new board leadership as Ron Hakes became Chairman and Danielle Fleumer stepped up as Vice Chair. And we witnessed leaders from across the nonprofit corporations volunteer to participate as NAVREF committee members, work group members, presenters, mentors, and subject-matter experts. Thank you all for your selflessness and dedication to serving veterans--you keep me inspired!

#### How are we doing?

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





# NAVREF ANNUAL REPORT 2020



# 2019-2020 Recognitions



#### **5<sup>TH</sup> ANNUAL NAVREF AWARDS**

We were proud to recognize three standout Executive Directors for their distinguished service and innovation at our 5<sup>th</sup> Annual Awards Dinner in San Antonio, Texas. (Picture of the 2019 NAVREF awards winners. From left to right: Ms. Danielle Fleumer; Ms. Angie Smith; Ms. Ashley Philipps)



NAVREF challenge coin commissioned in 2019 to honor distinguished supporters of NAVREF and veterans research

#### The Barbara West Award for Distinguished Service

Danielle Fleumer, Executive Director
Seattle Institute for Biomedical & Clinical Research

#### The Board of Directors Distinguished Service Award

Teresa "Angie" Smith, Executive Director North Florida Foundation for Research & Education

#### The Innovation and Best Practices Award

Ashley Phillips, Executive Director Middle Tennessee Research Institute

#### NAVREF Champion | \$100,000 and Up

#### **COHEN VETERANS BIOSCIENCE**

Cohen Veterans Bioscience stepped up in a big way in 2020 to provide financial support for our clinical trial facilitator role. Magali Haas and her team have been supporters of the ACT for Veterans initiative since the very beginning and we send a huge thank you to CVB for their generous support and patience.



# 👌 Philanthropic Donors

**NAVREF Star** | \$20,000 to \$99,999

**ASSOCIATION OF VA HEMATOLOGY AND ONCOLOGY** 



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 Hero | \$10,000 to \$19,999 We still need a hero!

#### **NAVREF Friend** | \$1,000 to \$9,999

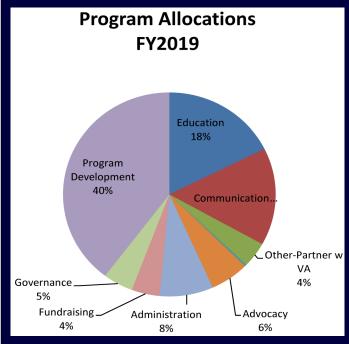
Alliance for Artificial Intelligence in Healthcare The Conafay Group Jeff Jakubiak

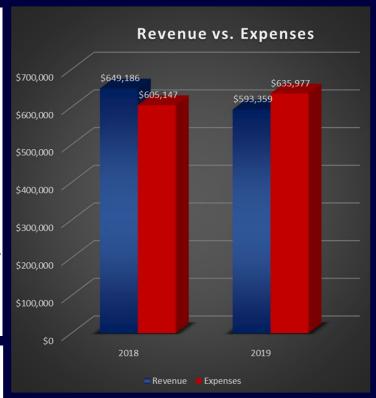
ce Mary Sano, PhD Microsoft Syneos Health Vietnam Veterans of America

#### NAVREF Ally | Up to \$999

Shelley Cobb • Danielle Fleumer • Robert Forrester • Scott Gruber • Ron Hakes Kevin Hull • Kent Kester • B. James McCallum • Jeffrey Moore • Kelly Page Mike Quinata • Cindy Reutzel • Robin Rusconi • Paul Russo

# **NAVREF** Financials





NAVREF continues our commitment to provide members with a resilient and strong association in support of our community's unique needs. Although FY 2019 saw a rise in expenses, those resources were used to ramp up program

enhancements and organizational growth. Investments were made into our education program, notably expanding our eLearning capacity as well as bringing in institutional experts in the areas of nonprofit development and Pre/Post Award Grant Management. Members also experienced dues reductions across the board and over a fifty percent reduction in their conference registration fees. These resources were also channeled towards stronger fundraising efforts through an experienced consultant in tandem with enhancing the ACT for Veterans Initiative footprint. The culmination of this effort ultimately helped produce the new Partnered Research Program within the Department of Veterans Affairs Office of Research and Development.

## On the Horizon For 2020-2021

The upcoming membership year will be unlike any other as we adopt new practices and processes to adjust to life with/after COVID-19. We will offer flexible payment terms so all members can maintain membership without undue financial pressure. We will host our 2020 Annual Conference virtually instead of returning to our home-away-from-home at the Ritz-Carlton Pentagon City. We will continue to actively pursue enhanced access to clinical trials for veterans at VA facilities through the Partnered Research Program and the ACT for Veterans initiative by focusing on streamlined start-up activities and improved enrollment practices. We will convene stakeholder meetings to help VA become industry's partner of choice for research. We will remain laser focused on our mission to advance the success of every NPC while we strive to become a nation in which veterans receive the finest care based on innovative research and education.

