PALs
UNITED
Patient Advocacy Leaders
United for Veterans' Health

PALs United for Veterans' Health Roundtable – Moving Ideas to Action 2022

The **Patient Advocacy Leaders (PALs) United for Veterans' Health Roundtable: Addressing the Issues Affecting Veterans with Rare Diseases/Conditions** event was held on November 16, 2021. This virtual event convened a select group of over 25 veterans' advocates and health leaders to collaborate on ways to improve access to care for U.S. Veterans affected by rare diseases/conditions. The overarching goal of the roundtable event was to help build better collaboration between and among those committed to the health and well-being of veterans. Key objectives included:

- Coalesce advocates and supporters from veteran service organizations, rare disease patient health advocacy groups, caregivers, and/or provider organizations, to identify ways of working together to meet the access, diagnostic, and treatment challenges and disparities specific to rare disease within the VA Health Care system.
- Connect the group of advocates so that they can formulate a framework focused on awareness, education, and advocacy for policy development and/or procedural change within the VA to address access to care for veterans affected by rare disease/conditions.

Attendees heard from the speakers listed below, and then participated in interactive and targeted breakout sessions. The event was moderated by **Dr. Glenna Crooks,** President, Strategic Health Policy International.

- **Jamie Sullivan**, Director of Public Policy for the EveryLife Foundation for Rare Diseases, a nonprofit organization dedicated to empowering the rare disease patient community to advocate for science-driven legislation and policy that advance access to diagnoses, treatments, and cures. Ms. Sullivan provided an overview on the impact of rare diseases and some challenges in diagnosing and accessing care. Over 7,000 rare diseases impact roughly 30 million individuals in the U.S. and over 90 percent of rare diseases have no approved treatment option.

- **Chet Edwards**, a former member of Congress and a partner in Edwards, Davis Stover & Associates, a government relations consulting firm located in McLean, Virginia. Mr. Edwards shared lessons learned and suggestions for effective advocacy in support of veterans with rare diseases.

The breakout sessions focused on policy and educational issues. One group focused on identifying policy and advocacy issues involved in building support within the U.S. Department of Veterans Affairs (VA) for access to effective and equitable treatments and support for veterans with rare diseases. Another group focused on identifying educational and awareness materials and strategies to be used with the VA to improve their understanding of rare disease patient needs and for patients/caregivers and providers to better access and advocate for science-based treatments for their rare disease/condition.

The event concluded with a Group Discussion "*Making it Happen – What Now*?" focused on actionable next steps, led by **Rick Weidman**, Executive Director Emeritus of the Vietnam Veterans of America and Dr. Crooks.

In the months following the event, the **Center for Patient Advocacy Leaders** has engaged with event participants to review recommendations made at the Roundtable to rate the importance of each in terms of how they should be prioritized for possible action. Below are the results of the survey.

POLICY Recommendations rated by importance of how they should be prioritized for future action:

	VERY IMPORTANT	IMPORTANT	NEUTRAL	LOW IMPORTANCE	NOT AT ALL IMPORTANT
Improve care for women veterans	83.00%	17.00%	0.00%	0.00%	0.00%
Expand care in community-based and rural settings	67.00%	33.00%	0.00%	0.00%	0.00%
Increase transparency of decision-making for formulary changes to allow for more effective advocacy	67.00%	33.00%	0.00%	0.00%	0.00%
Improve cultural competency among healthcare providers	50.00%	50.00%	0.00%	0.00%	0.00%
Increase access to telehealth	50.00%	50.00%	0.00%	0.00%	0.00%

EDUCATION Recommendations rated by importance of how they should be prioritized for future action:

	VERY IMPORTANT	IMPORTANT	NEUTRAL	LOW IMPORTANCE	NOT AT ALL IMPORTANT
Build capacity of veterans & caregivers to advocate using storytelling	50.00%	50.00%	0.00%	0.00%	0.00%
Educate healthcare providers about rare diseases and needs of veterans	50.00%	50.00%	0.00%	0.00%	0.00%
Create a centralized location for rare disease information & resources	17.00%	83.00%	0.00%	0.00%	0.00%

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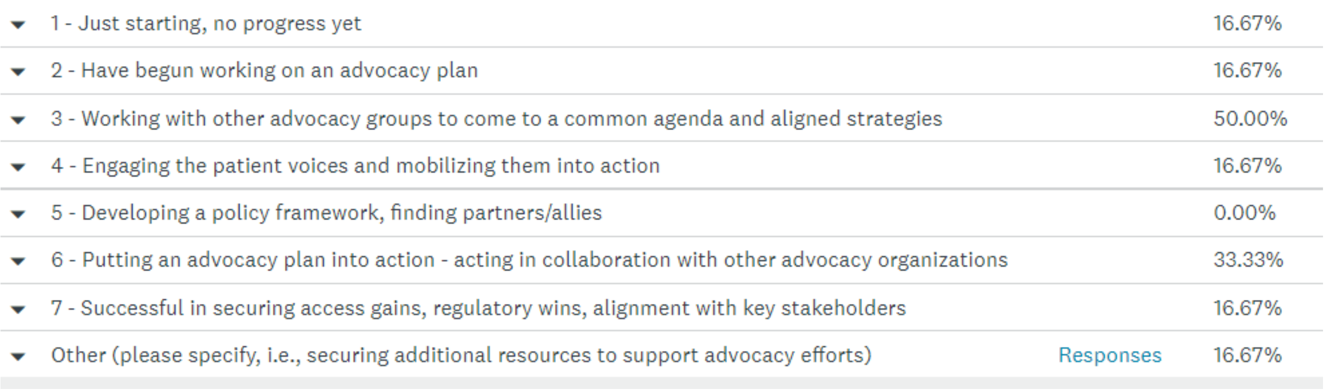
Recommended NEXT STEPS suggested by collective group, rated by importance of how they should be prioritized for future action:

	VERY IMPORTANT	IMPORTANT	NEUTRAL	LOW IMPORTANCE	NOT AT ALL IMPORTANT
Engage diverse stakeholders in advocacy efforts including: Patients & Caregivers; Health & Veteran Advocacy Groups; Professional Societies; Veterans Health Council	67.00%	33.00%	0.00%	0.00%	0.00%
Connect, empower and coalesce veterans to build trust, credibility, and a network that will allow for better advocacy for rare disease care	67.00%	33.00%	0.00%	0.00%	0.00%
Agree on several specific policy goals and speak with a common voice to make the most impact. Suggested Goal 1: Improve access to treatment and specialists (including those outside the VA system) for veterans	67.00%	33.00%	0.00%	0.00%	0.00%
Agree on several specific policy goals and speak with a common voice to make the most impact	83.00%	17.00%	0.00%	0.00%	0.00%

Suggested Goal 2: Improve access to treatment and specialists (including those outside the VA system) for veterans					
Agree on several specific policy goals and speak with a common voice to make the most impact. Suggested Goal 3: Identify and address bottlenecks in the VA	67.00%	33.00%	0.00%	0.00%	0.00%

Attendees were asked to rate their **effectiveness** regarding their advocacy work relating to addressing issues affecting Veterans with rare diseases/conditions.



1 - Just starting, no progress yet	16.67%
2 - Have begun working on an advocacy plan	16.67%
3 - Working with other advocacy groups to come to a common agenda and aligned strategies	50.00%
4 - Engaging the patient voices and mobilizing them into action	16.67%
5 - Developing a policy framework, finding partners/allies	0.00%
6 - Putting an advocacy plan into action - acting in collaboration with other advocacy organizations	33.33%
7 - Successful in securing access gains, regulatory wins, alignment with key stakeholders	16.67%
Other (please specify, i.e., securing additional resources to support advocacy efforts) Responses	16.67%

Final Thoughts

A review of the Roundtable proceedings report and the responses from the participants relating to next steps demonstrate a readiness for both veterans service organizations and rare disease health advocates to move forward in a number of collaborative areas. In addition, the collaboration among veterans and rare disease health advocates is at an early stage, that can be fostered so that both groups become stronger in their work. The objectives identified at the outset of the Roundtable have only begun to be met. This coalition in its formative stage has the potential to be built into an effective advocacy group that is focused on veterans' health and their families, especially the population affected by rare disease. With help from CPALs, the objectives, over time, can be fully realized. A snapshot of the energy from the first meeting of this group was captured when attendees were asked to provide one or two words to describe their thoughts about the event. Responses are depicted in the word cloud and comments from attendees below.

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"As a veteran and President of RetireSafe I feel that the Roundtable was very valuable. The discussion on rare diseases and how veterans are now becoming a point of concern inspired hope. Many veterans live in rural areas where treatment is hard to come by. We need to bring this concern to our legislators and increase funding for more accessibility for these veterans. RetireSafe will continue to support efforts of PALs."

Mark Gibbons
President, RetireSafe

"After meeting all the attendees and listening to their stories and opinions, my big take away from the meeting was a feeling that I am not alone, not unlike how our patients must feel when they come to one of our Amyloidosis Support Group Meetings. We have so many issues, but I constantly must remind myself to stay focused as we were so kindly, and often, advised by Congressman Edwards. He seemed to me to be incredibly wise indeed."

Muriel Finkel
President, Amyloidosis Support Groups Inc.

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ADVOCACY LEADERS
By Advocates, For Advocates

*The **Center for Patient Advocacy Leaders** (CPALs), a collaborative initiative of The AIDS Institute, (TAI), is dedicated to improving the lives of those affected by disease and chronic health conditions of all types by educating and mobilizing health advocacy leaders to work collaboratively in developing impactful policy and advocacy solutions to timely health care issues. CPALs facilitates engagement, collaboration, and a model that promotes patient-centered, quality, affordable healthcare for all people. CPALs utilizes an advocate-centered model, "By Advocates, For Advocates" that focuses on the needs of patients and caregivers, patient advocacy leaders, their organizations, and the diverse communities they serve. The emphasis is on forming long-term meaningful partnerships involving multiple sectors and stakeholders around a common agenda.*