



**PALs
UNITED**

Patient Advocacy Leaders
United for Veterans' Health

***Patient Advocacy Leaders United for Veterans' Health Roundtable:
Addressing the Issues Affecting Veterans with Rare Disease/Conditions***

A program of the Center for Patient Advocacy Leaders (CPALs)

***3:00 pm – 5:00 pm EST
November 16, 2021***

OBJECTIVES

- ② Coalesce advocates and supporters from veteran service organizations, rare disease patient health advocacy groups and caregivers, 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.
- ② Connect the group of advocates so that they can formulate a framework focused on awareness and 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.

3:00 pm – 3:10 pm Welcoming Remarks & Introductions

***Glenna Crooks, PhD – Moderator
President, Strategic Health Policy International, Inc.
Former, Deputy Assistant Secretary for Health
Former Chair, National Commission on Rare Diseases
Awardee, Congressional Exemplary Service Award for Orphan Products
Development***

3:10 pm – 3:30 pm Overview of the Current Healthcare Landscape Relating to Rare Disease Care in the Veterans Community

Chet Edwards, Former Congressman

***Jamie Sullivan, MPH
Director of Public Policy, EveryLife Foundation for Rare Diseases***

3:30 pm – 3:45 pm Moderator Facilitated Q&A



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By Advocates, For Advocates



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3:45 pm – 4:15 pm **Finding Common Ground to Collaborate for Collective Impact**

 **3:45 – 4:00 – Breakouts**

Group 1- Identify **policy and advocacy issues** involved in building support in the VA for access to effective and equitable treatments and support for veterans with rare diseases.

Group 2 - Identify **educational and awareness** materials and strategies for 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 (getting the right treatment at the right time in the right place). If no/few such materials exist, identify the gaps we need to fill.

 **4:00 – 4:15 – Reporting Out from Breakouts**

4:15 pm – 4:50 pm **Making it Happen – What Now? (Group Discussion)**

Rick Weidman – Session Facilitator

Executive Director Emeritus, Vietnam Veterans of America (VVA)

4:50 pm - 5:00 pm **Wrap Up – Glenna Crooks**

5:00 pm **Event Concludes**

Thank you to our partners who helped make this event possible!

