



**PALs  
UNITED**

Patient Advocacy Leaders  
United for Veterans' Health

***Patient Advocacy Leaders United for Veterans' Health Advocacy Roundtable:  
Collaborating on Issues Affecting Veterans with Rare Diseases to  
Maximize Collective Impact***

***A Program of the Center for Patient Advocacy Leaders (CPALs)***

***1:30 pm – 3:30 pm ET  
December 8, 2022***

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**OBJECTIVES**

- 🕒 Examine and clarify potential barriers and their solutions to achieve the goals identified through *PALs United for Veterans' Health* in order to improve the health of Veterans with rare diseases receiving care through the VA health care system.
- 🕒 Utilize the information and insights shared during group discussions to enhance the *PALs United for Veterans' Health Blueprint for Action*.
- 🕒 Identify next steps and resources that will enable advocates to collaborate and mobilize to achieve the outlined goals, with additional information incorporated into the *PALs United for Veterans' Health Blueprint for Action*, a roadmap to maximize collective impact.

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1:30 pm – 1:40 pm	<b>Welcoming Remarks - <i>Glenna Crooks, PhD – Moderator</i></b>
1:40 pm – 1:55 pm	<b>Where We've Come From; Where We're Going to Support Veterans with Rare Diseases - <i>Glenna Crooks, PhD</i></b>
1:55 pm – 2:35 pm	<b>Interactive Dialogue Sessions to Discuss Goals <i>Held Concurrently with Group Report Outs to Follow</i></b>



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CENTER FOR PATIENT  
ADVOCACY LEADERS  
*By Advocates, For Advocates*



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### **Dialogue Session 1**

**Goal #1- Timely diagnosis, treatment, and supportive care, including in community-based settings and/or rural communities**

**Moderator:**

*Edward (Ed) V. Hickey - President, American Association of Kidney Patients (AAKP); Chair, AAKP Veterans Health Initiative, USMC*

### **Dialogue Session 2**

**Goal #2- Accelerated access to treatments and supportive therapies and services**

**Moderator:**

*Elizabeth (Hale) Simpson, MPA – Rare Diseases Working Group Manager/Health Advocacy Manager, Alliance for Patient Access*

### **Dialogue Session 3**

**Goal #3- Improved rare disease awareness, education, information, and advocacy within the Veterans' and rare disease communities**

**Moderator:**

*Mark Gibbons, President/CEO, RetireSafe*

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| 2:35 pm – 3:20 pm | <b>Dialogue Session Report Outs and Group Discussion</b><br><i>5-minute Report Outs + 10-minute Group Discussions for each Goal</i> |
| 3:20 pm – 3:30 pm | <b>Next Steps: Where We're Going – Using the Blueprint for Collective Action -</b><br><i>Glenna Crooks, PhD</i>                     |
| 3:30 pm           | <b>Event Concludes</b>  |

*The Center for Patient Advocacy Leaders is an evolution of a program called PALS that was developed in 2002. Since 2016 CPALS has been housed within The AIDS Institute. Work continues to be across disease states and populations, and driven by an advocate-centered model, By Advocates, For Advocates. For more information, please visit the CPALS website at <https://www.centerforpatientadvocacyleaders.org/>.*



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