



**PALs
UNITED**

*Patient Advocacy Leaders
United for Veterans' Health*

Improving Care for Veterans with Rare Diseases: A Blueprint for Action Summary Goals

Goal #1: Timely diagnosis, treatment, and supportive care, including in community-based settings and rural areas

Veterans' Needs	Solutions
Timely Diagnosis	<ul style="list-style-type: none"> As the largest integrated health system in the nation, VHA should leverage EHR data, clinical expertise, and health risk assessments, to develop and implement protocols to expedite the diagnosis of rare diseases, particularly those which are more common to Veterans. VHA should conduct a study of Veterans diagnosed with rare diseases to explore their diagnostic journey, identify any barriers to timely diagnosis, and recommend process improvements for the benefit of Veterans who are not yet diagnosed. VHA should provide access to appropriate genetic testing and counseling when a rare disease is suspected. VHA should replicate the NIH Undiagnosed Network to address the challenges of rare disease diagnoses in Veterans.
Access to Specialists	<ul style="list-style-type: none"> VHA should routinely support access to specialists within local communities and medical centers and should continue to maintain its provider search site (https://www.va.gov/health/ourdoctors.asp) along with the DocInfo services of the Federation of State Medical Boards (https://www.docinfo.org/), and provide Veterans access to those clinical resources regardless of their location. VHA should make widespread, easy access to telemedicine, provide parity payments for telemedicine visits, and allow low-tech options (e.g., by telephone for those who do not have access to high-speed internet or smartphones) a matter of permanent policy.
Comprehensive Care	<ul style="list-style-type: none"> VHA should ensure that care for Veterans integrates the medical, behavioral health, and social service needs in a Veteran-centric team approach. VHA should search its electronic medical records to identify Veterans who have been diagnosed with rare diseases and should assess whether they have unmet needs. VHA should ensure that professional VHA Patient Advocates have been trained on rare diseases and the challenges patients have in securing a timely diagnosis and comprehensive care. They should be armed with information about how to reach out to rare disease groups to secure information about referral networks and should help Veterans and their caregivers who want to connect with those groups.

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Goal #2: Accelerated access to treatments and supportive therapies

Veterans' Needs	Solutions
Quality Care	<ul style="list-style-type: none"> VHA should reach out to those already diagnosed to identify any unmet needs. VHA should establish a registry to track Veterans with rare diseases and their diagnostic and treatment experiences to identify areas of improvement.
New Therapeutics	<ul style="list-style-type: none"> VHA should support the passage of the STAT Act. Empower patients to develop an impactful voice in policymaking, drug development, and regulatory decision-making.
Access to Approved Therapeutics	<ul style="list-style-type: none"> VHA should remove all step-therapy, co-pay, and cost-sharing barriers for Veterans with rare diseases by providing first-dollar coverage and full reimbursement for any FDA-approved therapeutic or other medication selected by their physician.

Goal #3: Improved rare disease awareness, education, information, and advocacy

Veterans' Needs	Solutions
Greater Visibility	<ul style="list-style-type: none"> Veterans and rare disease organizations should collaborate to develop a repository of personal stories of veterans with rare diseases, their caregivers, and their clinicians. Veterans and rare disease organizations should conduct awareness and education programs to inform the general public about rare diseases in Veterans and the impact on them, their families, and their employers, especially in communities with military installations and in the top five most populous States for Veterans: TX, FL, CA, PA, and VA.
Information	<ul style="list-style-type: none"> VHA should develop a centralized, easily searchable resource with information about rare disease diagnosis, care, and benefits for Veterans and caregivers. Rare Disease Advocacy groups should develop health-literate information and submit those resources to the VA's National Resource Directory: https://www.nrd.gov/. Rare Disease Advocacy groups that may have Veterans within their patient population should highlight their support of Veterans on their web platforms and in their programs. Veteran and rare disease stakeholders should meet regularly to learn from one another and collaborate on finding solutions to common problems. Rare disease and Veterans' groups should jointly connect with advocacy organizations and professional societies that may have an interest in rare diseases to educate members and raise awareness, e.g., American Thoracic Society's Public Advisory Roundtable; Consortium for Citizens with Disabilities; Medical associations, including those that focus on underserved populations; AARP; and American Diabetes Association VHA should develop a platform for Veteran-to-Veteran connections, assuring Veterans with rare diseases who want to connect with other Veterans are able to do that.