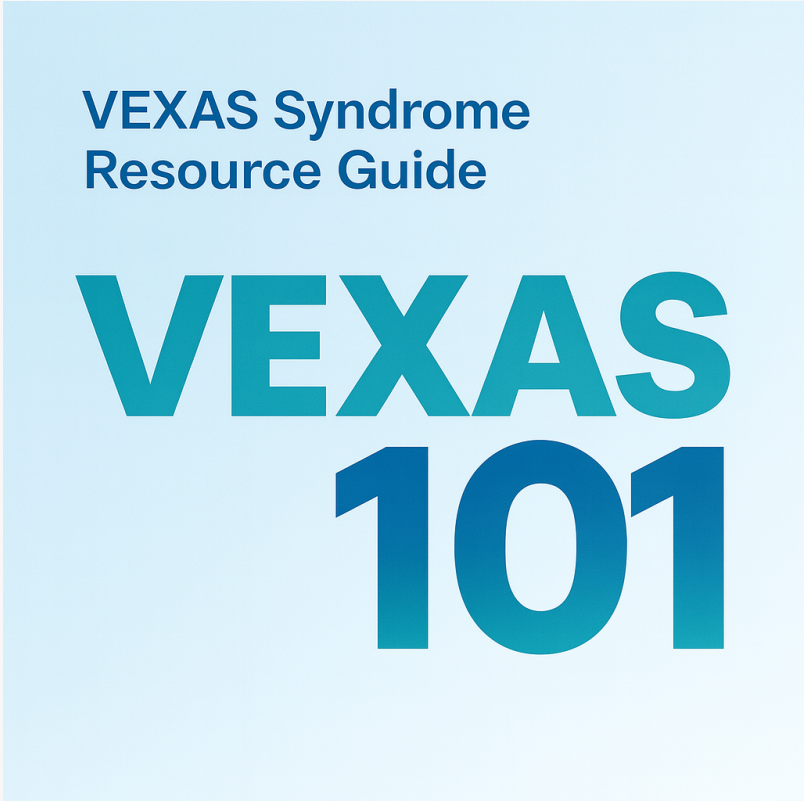
The VEXAS Foundation Announces Release of 'VEXAS 101' Syndrome Resource Guide

VEXAS 101 provides reliable information to help shorten diagnosis time, improve care, and support better outcomes.



VEXAS 101

NEW YORK, NY, UNITED STATES, November 11, 2025 / EINPresswire.com/ -- The VEXAS Foundation today announced the official release of the VEXAS 101 Resource Guide: a comprehensive educational resource nearly a year in development and the product of hundreds of hours of dedicated work.

Named “VEXAS 101” to reflect its purpose as a foundational introduction to the disease, the guide provides clear, reliable information about VEXAS syndrome, including symptoms, diagnosis pathways, and current treatment approaches. Its core goal is to raise awareness, shorten the time to diagnosis, and help support improved clinical care and patient outcomes.

The Foundation extends deep gratitude to the many contributors who made this publication possible, with special recognition to Dr. David Beck (NYU), Dr. Mathew Koster (Mayo Clinic), and Mei-Kay Wong (NYU), whose scientific expertise and thoughtful review were invaluable. The Foundation also recognizes its donors and supporters, whose generosity funded this critical resource.

The Foundation intends to update VEXAS 101 regularly and invites feedback and suggestions from readers.

The guide is now available here: VEXAS 101 Guidebook

(Printed copies are available to medical professionals upon request)

What is VEXAS Syndrome?
VEXAS syndrome was first identified in 2020 at the National Institutes of Health (NIH)(1). It is a rare, adult-onset autoinflammatory disease impacting multiple organ systems, including the skin, lungs, bone marrow, cartilage, eyes, and blood vessels. VEXAS symptoms frequently resemble other conditions—such as relapsing polychondritis, vasculitis, and myelodysplastic syndrome (MDS). In a Foundation survey, 73% of VEXAS patients reported being initially misdiagnosed, which contributed to delayed and incorrect treatment. Because many VEXAS patients are older adults, timely diagnosis is often the difference between manageable treatment and life-threatening complications.

Mortality remains high. Studies show that up to half of patients die within five years of diagnosis. Overall mortality is approximately 27%, with a median survival of 10 years from symptom onset.

While considered rare, emerging research suggests VEXAS syndrome may be significantly more common than initially believed. In the United States, approximately 1 in 4,269 men over 50 years old—and 1 in 26,238 women over 50—may have VEXAS. Globally, it may affect more than a million people.

About the VEXAS Foundation
Founded in 2022, the VEXAS Foundation Inc. is the first nonprofit organization dedicated solely to improving the lives of individuals living with VEXAS syndrome. The Foundation advances this mission by raising awareness, supporting research, and accelerating efforts that lead to earlier diagnosis, improved treatment, and ultimately, a cure for VEXAS syndrome.

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