

**FOR IMMEDIATE RELEASE**

**CONTACT:**

PR: **Sandra Goroff**

Email: [sgma@aol.com](mailto:sgma@aol.com)

Phone Number: 617-750-0555

Treasurer of the Board: **Tanya M. Holton**

Email: [tanya@malsfoundation.org](mailto:tanya@malsfoundation.org)

Geographic Area: Boston Area

***Note to journalists: Tanya Holton is available to interview. She has been a MALS patient.***

Secretary of the Board: **Laura Gilmore**

Email: [laura@malsfoundation.org](mailto:laura@malsfoundation.org)

Geographic Area: Colorado Springs/Denver area

***Note to journalists: Laura Gilmore is available to interview. She has been a MALS patient since she was a child.***

Vice President of the Board: **Robin Insley Schrader**

Email: [robin@malsfoundation.org](mailto:robin@malsfoundation.org)

Geographic Area: Baltimore/Washington DC area

***Note to journalists: Robin Insley Schrader is available to interview. She has been a MALS patient.***

President of the Board: **Suzanne Peek**

Email: [suzanne@malsfoundation.org](mailto:suzanne@malsfoundation.org)

Geographic Area: Philadelphia/Harrisburg

***Note to journalists: Suzanne Peek is available to interview. She has a son who was a MALS patient.***

**Thursday, Feb. 17, is Designated as “National MALS Awareness Day”  
To Help Create Awareness of and Advocacy For, Education and Research Into The Rare  
and Misunderstood Disease That Affects Thousands of Americans**

Thursday, Feb. 17, has been designated as National MALS Awareness Day, to help create awareness of the rare and misunderstood disease, Median Arcuate Ligament Syndrome (MALS), also known as Celiac Artery Compression Syndrome and Dunbar Syndrome. According to the **National MALS Foundation**, MALS is a disorder that is characterized by varying degrees of intermittent or chronic abdominal pain, gastrointestinal symptoms, and exercise intolerance. While rare, it is known to affect thousands of Americans, and that number is growing as more exacting diagnosis techniques, details of which are being provided to the medical community by the National MALS Foundation, come to bear.

The Foundation earlier had created and released an educational video in partnership with Osmosis.org and the National Organization for Rare Disorders (NORD), that the Foundation hopes will help more clinicians understand this rare condition and ensure that patients move more rapidly toward diagnosis.

Many patients suffer for months or years seeking a MALS diagnosis because so few clinicians have learned about the condition or consider it too rare to be a factor in patients' abdominal pain. The creation of this video and distribution of it onto both the [Osmosis.org](https://www.osmosis.org) platform and [\*NORD rare disease video library\*](#) will ensure that more clinicians have access to information about the causes and symptoms of MALS, and will provide information for patients to take to their clinicians in seeking a diagnosis and care plan.

The National MALS Foundation ([www.malsfoundation.org](http://www.malsfoundation.org)) is a nonprofit organization dedicated to the mission of providing hope and support - body, mind and spirit - to those suffering from the debilitating symptoms of MALS through advocacy, awareness, education, and research within the clinical and mainstream communities. The Foundation, established in 2018, has been instrumental in bringing awareness to the condition and the processes for seeking a diagnosis. In addition to getting recognition for MALS as a rare condition by the National Organization for Rare Disorders, the MALS Foundation is also listed on the NIH Genetic and Rare Diseases Information Center database (GARD) as a trusted supporting organization for Median Arcuate Ligament Syndrome (MALS).

### **About Osmosis.org**

Osmosis.org is a health education platform that empowers millions of current and future clinicians and caregivers with the best learning experience possible. As pioneers in health education technology, Osmosis takes learning beyond textbooks and lectures by offering online educational video content that's simple, engaging, and informative. Osmosis.org has a library of over 2,100 videos covering pathology, physiology, pharmacology, and clinical practice, complete with questions, flashcards, and notes. For more information, visit [www.osmosis.org](http://www.osmosis.org).

### **About the National Organization for Rare Disorders (NORD)**

The National Organization for Rare Disorders ([www.rarediseases.org](http://www.rarediseases.org)) is the leading independent advocacy organization representing all patients and families affected by rare diseases in the United States. NORD began as a small group of patient advocates that formed a coalition to unify and mobilize support to pass the Orphan Drug Act of 1983. Since then, the organization has led the way in voicing the needs of the rare disease community, driving supportive policies, furthering education, advancing medical research, and providing patient and family services for those who need them most. Together with over 300 disease-specific member organizations, more than 15,000 Rare Action Network advocates across all 50 states, and national and global partners,