FOR IMMEDIATE RELEASE

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National MALS Foundation designates Friday, February 17, 2023, as

MALS Awareness Day to bring awareness to the debilitating medical condition of

Median Arcuate Ligament Syndrome

Stouchsburg, Pennsylvania, United States -- The National MALS Foundation has announced that Friday, February 17, 2023, is designated as national awareness day for the medical condition known as Median Arcuate Ligament Syndrome (MALS). This day was selected to honor February 1917, the month and year that MALS compression was first documented. Even though MALS has been known for 105 years, it is still not a well known medical condition. In celebrating MALS Awareness Day in 2023, the foundation will be helping to bring awareness to a condition that needs more attention from clinicians because it can have a devastating effect on patients.

Median Arcuate Ligament Syndrome (MALS), also known as celiac artery compression syndrome, is a disorder that is characterized by varying degrees of intermittent or chronic abdominal pain, gastrointestinal symptoms, and exercise intolerance. In scientific studies, MALS has been found in 2 out of 100,000 patients,¹ and yet is believed to affect many more who have suffered without diagnosis. As the MALS Foundation Clinical Advisory Board member, Dr. Christopher Skelly, recently wrote in the Journal of Vascular Surgery, "MALS is not rare; rather, it is rarely diagnosed and treated. When treating MALS, vascular surgeons [and other clinicians] need to consider a diagnosis they tend to avoid: chronic abdominal pain."² The MALS Foundation is advocating that those who suffer with undiagnosed chronic abdominal pain should be evaluated for MALS.

While MALS has a reputation as affecting only women, the reality is that MALS affects all genders, ages, and body types. Many MALS patients suffer for months or years seeking a diagnosis because so few clinicians have learned about the condition or consider it too rare to be a factor in patients' abdominal pain. In 2021, the MALS

¹ lobst T P, Lamb K M, Spitzer S L, et al. (February 10, 2022) Median Arcuate Ligament Syndrome. Cureus 14(2): e22106. doi:10.7759/cureus.22106

² Skelly C, Mak G (February 2023) Invited Commentary, Median arcuate ligament syndrome: surgical approaches to a rarely diagnosed and undertreated disease. J Vasc Surg 2023;77:578-9 doi:10.1016/j.jvs.2022.11.046

Foundation created and distributed an educational video on the Osmosis platform and through the NORD rare disease video library that is also designed to provide clinicians and patients with information about the causes and symptoms of MALS. The video can be viewed at: https://www.malsfoundation.org/resources.

The National MALS Foundation <u>Clinical Advisory Board</u> includes the following MALS experts from around the country: Dr. David Dickerson, NorthShore University Health System in Chicago; Dr. Kevin El-Hayek, MetroHealth System in Cleveland, Ohio; Dr. Gustav Oderich, The University of Texas Health Science Center at Houston; Dr. Woosup Michael Park; Dr. Christopher Skelly, University of Chicago Medical Center; Dr. Daniel Shouhed, Los Angeles.

The National MALS Foundation, established in 2018, has been instrumental in bringing awareness to the condition and the processes for seeking a diagnosis. It 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. It does this through advocacy, awareness, education, and research within the clinical and mainstream communities. View their website at www.malsfoundation.org.

If you seek MALS patients to interview, we can help identify someone in any region of the country.

For select past media stories about MALS, see these resources:

Channel 5 News, Cleveland, February 24, 2022, "Woman living with rare disease shares importance of being your own advocate"

https://www.news5cleveland.com/lifestyle/health-and-fitness/woman-living-with-rare-disease-shares-importance-of-being-your-own-advocate

US News, March 25, 2018, "After Years, Virginia Woman Finds Answer to Mystery Illness" [profile of Robin Insley Schrader, contact above]

https://www.usnews.com/news/best-states/virginia/articles/2018-03-25/after-years-virginia-woman-finds-answer-to-mystery-illness

The Washington Post, September 26, 2016, "Pain kept this young woman from eating for five years, and doctors didn't know why"

https://www.washingtonpost.com/national/health-science/pain-kept-this-young-woman-from-eating-for-5-years-and-doctors-didnt-know-why/2016/09/26/399211a6-6df9-11e6-9705-23e51a2f424d story.html?noredirect=on&utm term=.a20d2b536e9a