Martin Mueller IV

For over twenty years, Martin Mueller IV dedicated himself to supporting people with achalasia. He provided an online presence which offered a forum for discussion for patients to share and compare their experiences. Discussions included procedures people were undergoing and whether or not the results were successful in helping people to manage and cope with this disease. Over the years, people in similar circumstances who felt isolated and who recognized a lack of information and support, asked Martin to formally head a foundation. This organization would serve to help and support him in his work and further the mission of achalasia awareness, support for patients, caregivers, spouses, families, and the medical community, while promoting research at the same time. In 2010, the foundation was started by Martin and the name - The Martin Mueller IV Achalasia Awareness Foundation - was chosen by board members, thought to be the most fitting, to continue the work that Martin started many years before.

The goal of the Martin Mueller IV Achalasia Awareness Foundation, Inc (MMIVAAF) is to further education, awareness and research of the esophageal disease achalasia.
MMIVAAF is a non-exempt 501(C)(3) organization.

Partnered with:
National Organization for Rare Diseases (NORD)
Rare Diseases United Foundation
Rare Disease Day, U.S. Department of Defense

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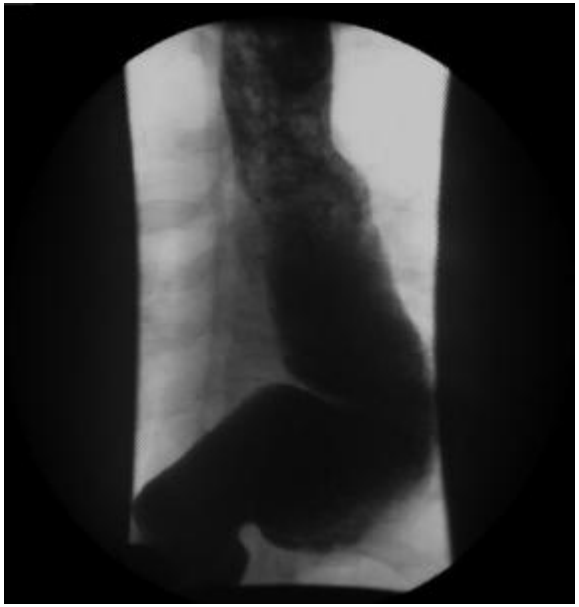
MMIVAAF does not provide medical advice.



ACHALASIA

What is achalasia?

Achalasia is a disorder of the esophagus that makes it difficult to swallow solid or liquid foods. The act of swallowing causes a wave or peristalsis in the esophagus. Peristalsis is the succession of waves of involuntary muscular contractions in the esophagus, stomach and the intestines, which transports food and waste products from the mouth to the colon. In achalasia, peristalsis in the esophagus is diminished, erratic or no longer functioning. This condition occurs when the lower esophageal sphincter (LES) (muscle located between the esophagus and the stomach) doesn't relax sufficiently, which makes it hard for food to pass from the esophagus into the stomach.

How rare is achalasia?

Achalasia is a rare disorder—only about 3,000 people in the U.S. are diagnosed each year. Because the condition is so rare, it's helpful to choose a medical center with experience in diagnosing and treating this disease.

What causes achalasia?

The cause is unknown, but may be related to a viral infection that attacks the nerves of the esophagus. Anxiety and emotional tension may aggravate achalasia and precipitate attacks.

Is achalasia autoimmune?

In 2014, researchers were able to pinpoint genetic alterations in some patients with achalasia to the same gene associated with other autoimmune disorders, including multiple sclerosis, type 1 diabetes and lupus. This evidence suggests that achalasia may be an autoimmune disease.

Is there a cure for achalasia?

At this time there is no known cure for achalasia, only management of symptoms, and treatments to help our long term health. Achalasia does not go away, your symptoms may subside sometimes, but the disease unfortunately does not go away.

Symptoms:

- Dysphagia (difficulty swallowing)
- Regurgitation of food
- Chest pain after eating
- Coughing and choking
- Weight loss
- Heartburn

Achalasia affect people differently. What aggravates or helps one person may not help the next. The average diagnosis time is between 5-7 years due to the changing symptoms as achalasia mimics more common diseases in the esophagus and stomach.

Diagnosing achalasia:

Proper diagnosis is the first step toward appropriate and effective treatment. Sometimes patients are incorrectly diagnosed as having reflux which does not get better with traditional reflux medication.

Barium X-ray – X-rays are taken after swallowing barium to show passage from the esophagus into the stomach. A narrowing or "bird's beak" appearance at the end of the esophagus is suggestive of achalasia.

Endoscopy - Insertion of a thin, flexible tube down the throat, through the esophagus and into the stomach. The endoscope is equipped with a tiny camera that enables the physician to actually see inside the esophagus and other organs. This test is important to make sure cancer or other diseases are not present.

High resolution Manometry - This test measures the strength and coordination of the muscles in the esophagus and definitively diagnoses achalasia. A very thin tube is passed through the nose and down to the stomach. The test then measures esophageal muscle function while the patient swallows sips of water. Manometry also evaluates the function and relaxation of the LES.

Treatments -

- Laparoscopic esophageal myotomy – minimally invasive surgical procedure performed through tiny incisions using miniaturized instruments. The surgeon severs muscles (myotomy) of the LES, making it easier for food and liquids to pass through.
- Per-oral Endoscopic Myotomy – (POEM) esophageal myotomy is done similar to conventional surgery, but with no external incision.
- Endoscopic dilation to widen the lower esophagus
- Botulin toxin (Botox) and injection to paralyze the sphincter muscle and prevent muscle spasms.
- Other medications typically used to relax the esophagus muscle.

Support

Tell your close friends and family about achalasia. It will help you cope with the condition and they can be more supportive if they understand the facts about the condition. This is your time to educate them on what you are going through.

While the cause of achalasia is unknown, the treatment options and effectiveness of each treatment depends on:

- Finding out early
- Get proper treatment right away