



ATS Medical Resources:

Listed below are some links and contacts for arterial tortuosity syndrome:

To find the latest information about arterial tortuosity syndrome, meet the medical advisory board, and the board of directors go to:

www.atwistoffate-ats.org

<https://www.omim.org/entry/208050>

[The ICD10 code for arterial tortuosity syndrome is Q87.82](#)

<https://www.icd10data.com/ICD10CM/Codes/Q00-Q99/Q80-Q89/Q87-/Q87.82>

There is a closed Facebook page for adult ATS patients and families:

<https://www.facebook.com/groups/138029982926649/>

Rare, but Strong!



What is our mission?

Our mission is to educate, promote awareness, support medical research, and ATS families.

Contact Our President/Founder for information about A Twist of Fate-ATS, any up to date information about past, present, and future Research, patient gatherings, and more.

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Find us on Facebook at:

https://www.facebook.com/ATSPatients/?epa=SEARCH_BOX



A Twist of Fate- ATS

Arterial Tortuosity Syndrome



What is Arterial Tortuosity Syndrome?

Arterial tortuosity syndrome (ATS) is a genetic, connective tissue-based disorder.

Arterial tortuosity syndrome (ATS) is an autosomal recessive, genetic, connective tissue syndrome, effecting the entire body. Typically, both parents of an affected patient must be carriers of the gene mutation, but on rare occasions other inheritance patterns are possible. Typically, if the two affected parents have more than one child with ATS, the other siblings will have a 1 in 4 chance of also having arterial tortuosity syndrome. The mutation occurs at the SLC2A10 gene, on the long arm of chromosome 20 (20q13.1).

Arterial tortuosity syndrome is known for causing the mid to large sized vessels to grow too long, kink, and twist, which can cause issues with the heart, lungs, and other organs. Joint hypermobility can make certain tasks more difficult, cause aches, pains, and/or fatigue. The eyes are also likely to be affected by ATS. The corneas can become thin and need special treatment and retinal detachment can be a concern. Another common issue are hernias, which can mostly be repaired.

How is ATS Diagnosed?

A clinical diagnosis may be given by a doctor, based on clinical findings, including symptoms, scans and procedures. Genetic testing must be done to confirm an ATS diagnosis, since there can be different treatment and surgical guidelines for similar connective tissue disorders.

What kind of Medical Care do we need?

We are working diligently to research and learn more about arterial tortuosity syndrome, daily. However, we are still defining the natural history and outcomes of ATS. Therefore, there are several core specialists that need to be part of your care team: Cardiology, Pulmonology, Gastroenterology, Nephrology, and Ophthalmology; other specialties may need to be added as symptoms arise. There are variations of each patient may experience. Sleep Apnea may be an issue for some patients, so they may need to have a sleep study, while others may have issues with hypermobility and need Occupational and/or Physical Therapy. Your doctors should use a team approach with medical care.

While there is not yet a "cure" for ATS, there are various medical treatments and Hope.



What is life like with ATS?

Life with arterial tortuosity syndrome can be fairly normal for most patients. Some of the patients with ATS are involved in swimming, Taekwondo, play musical instruments, and enjoy everyday activities. It is important to consult with your medical team to determine which physical activities should be limited and done with caution, or avoided all together. It is important to find activities that match the individual's ability and comfort level. There is so much hope for a bright future.

