Challenges, questions and possible group topics:

- How can we cope with this disease?
- How do our relatives cope with the chronic condition?
- Experiences with treatment
- Facilitation in everyday life
- Recognise your personal resources

www.helenesouza.com_pixelio.de

In our self-help group you will find many answers to your questions, people with similar experiences, tips for everyday life and perhaps new friends.

If you, as an affected person, are interested in an exchange with us, we would be pleased to receive a short message from you.

Best wishes from the Board and the members of Selbsthilfe Trachealstenose.

We are better together!

Member of:

ProRaris in Switzerland
Alliance of Rare Diseases
www.proraris.ch

Listed at:

NAKOS in Germany
BLUE ADDRESSES database
www.nakos.de/adressen/blau

Registered in:

SE-Atlas in Germany
Mapping of Health Care Providers for People with Rare Diseases
www.se-atlas.de/id/SE5428

www.trachealstenose.com

Atmen & Leben
Selbsthilfe
Trachealstenose

Tracheal stenosis

Idiopathic subglottic stenosis

When the air gets tight

Self-help tracheal stenosis

Who we are?

We are people affected by idiopathic progressive subglottic stenosis (iSGS). We live in Germany, Switzerland and Austria. In some cases, the cause of the stenosis is known.

What is a tracheal stenosis?

This condition is a slowly increasing narrowing of the windpipe. The cause is unknown, it is referred to as idiopathic stenosis.

The narrowing is called stenosis and is very rare with an estimate of only 1 in 400,000 people affected worldwide with 98% of this being women.

Tracheal stenosis is often misdiagnosed as asthma or as a psychosomatic disorder.

TO BREATHE IS TO LIVE

The community in our self-help group is a great tool for us to offer each other support and help build confidence, knowing we are not alone in dealing with this rare disease. It feels good to share our experiences online and in person, because

«TO BREATHE IS TO LIVE!»

In this group you will find ways to cope with and live with this disease.

Who are we aimed at?

We are looking for people with tracheal stenosis who would like to share their experiences.

Mutual support, maintaining contact with doctors and clinics and exchanging information are our main concerns.

On our homepage you will find lots of interesting information about idopathic tracheal stenosis and its treatment.

We would like to:

- Share experiences
- Exchange coping tips and strategies
- Positively impact everyday life, leisure time and family life through open and honest discussions
- To raise awareness of this rare disease and the treatment methods available, to ensure faster diagnosis and to find the most appropriate treatment for all in the future

How do we meet?

We meet digitally once a month and in person once or twice a year with discussions in German.

Are you interested? Then get in touch!

We look forward to meeting you!

www.trachealstenose.com

Self-help tracheal stenosis

www.trachealstenose.com

Swiss Association
Selbsthilfe Trachealstenose
trachealstenose@gmail.com

German Association
Selbsthilfe Trachealstenose e.V.
trachealstenose.de@gmail.com