

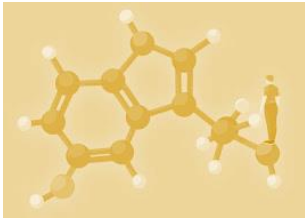


What did we learn about airway stenosis and its treatment during 2024?

Living with idiopathic subglottic stenosis (iSGS) support community:
www.facebook.com/groups/airwaystenosis

What we learned

1. Premenopausal patients have a more aggressive disease variant than postmenopausal counterparts



Reading:

“Association between Estrogen Exposure and Idiopathic Subglottic Stenosis”

Nainika Nanda, MD et al
The Laryngoscope, 134(2): 825-830,
February 2024
<https://doi.org/10.1002/lary.31030>

It has long been speculated that estrogen has a role to play in airway stenosis, particularly given the prevalence of females with the disease, compared to males (98% female to 2% male).

This research has revealed that patients who are peri and post menopause are more likely to have a longer surgery-free period than their pre-menopausal counterparts.

The researchers were unable to determine whether it is due to reduced estrogen, or whether it is more to do with age-related physiology of wound healing and inflammation, regardless of estrogen.

What this means

Once you reach peri and post menopause, you can potentially look forward to fewer dilations and an airway that stays open for longer.

What we learned

2. It takes an average of 21 months and four providers before an iSGS patient is correctly diagnosed



Reading:

“Navigating Pathways to Diagnosis in Idiopathic Subglottic Stenosis: A Qualitative Study”

Cara Damico Smith, MPH; Nainika Nanda, MD; Kemberlee Bonnet, MA; David Schlundt, PhD; Catherine Anderson, BA; Sara Fernandes-Taylor, PhD; Alexander Gelbard, MD; David O Francis, MD, MS
The Laryngoscope, 134(2): 815-824,
February 2024
<https://doi.org/10.1002/lary.31023>

96% of iSGS patients are initially misdiagnosed for their breathing issues, with asthma and allergies most common.

More than one in two patients were told their symptoms are psychosomatic or they are to blame for lack of symptom improvement (eg told they are not using inhalers properly, not losing weight etc).

Patients who are initially referred to an otolaryngologist by their primary health care provider/GP experience the shortest journey to diagnosis and treatment.

What this means

Education is key to help this change – is there any way that patients can share information with primary health care providers to bridge the gap?

Sharing the ‘Is it really asthma?’ flyer with providers who missed the right diagnosis may be a start on this journey.

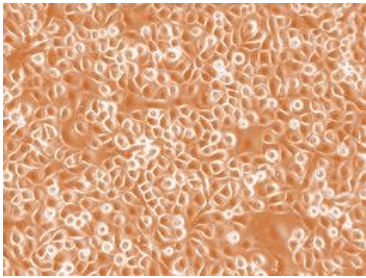


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What we learned

3. Researchers have found cellular changes in the airways of patients with iSGS



Reading:
“Transcriptional Profiling Sheds Light on the Fibrotic Aspects of Idiopathic Subglottic Tracheal Stenosis”
Martin Direeder; Maria Laggner; Dragan Copic; Katharina Klas; Daniel Bormann; Thomas Schweiger; Konrad Hoetzenecker; Clemens Aigner; Hendrik Jan Ankersmit; Michael Mildner
bioRxiv, February 2024
<https://doi.org/10.1101/2024.02.19.580975>

The researchers identified several important findings:

- **Fibroblasts** (a type of cell that creates scar tissue) were found to be in a "profibrotic" state, meaning they were contributing to the excessive scarring in the airway.
- **Schwann cells**, which are normally involved in nerve function, were also found in the scar tissue, and they appeared to be in a state that promotes fibrosis.
- There was an increased number of **plasma cells**, which are immune cells that produce antibodies and are often involved in inflammation.

The study also analysed changes in the extracellular matrix, which is the material that surrounds cells and provides structural support.

What this means

These findings suggest that ongoing fibrotic (scarring) processes are happening in iSGS and that certain cells, like fibroblasts, Schwann cells, and plasma cells, may play key roles in the disease.

It is hoped that understanding these cellular changes will help in developing better ways to diagnose and treat iSGS in the future.

What we learned

4. CO2 laser dilations result in longer periods between surgeries than cold-steel dilations



Reading:
“Laser Versus Cold Steel for Endoscopic Management of Subglottic Stenosis”
Kevin Y. Liang, MD; Katherine M. Miller, MD; Faez Syed, MD; Hong Li, MS; William S. Tierney, MD; Rebecca C. Nelson, MD; Michael S. Benninger, MD; Paul C. Bryson, MD, MBA; Robert R. Lorenz, MD, MBA
Otolaryngology - Head and Neck Surgery, 171(2): 471-477, March 2024
<https://doi.org/10.1002/ohn.727>

This study compares the effectiveness of two techniques for treating subglottic stenosis: using carbon dioxide (CO2) laser versus cold steel (a traditional surgical technique with sharp instruments).

The study found that the time without needing another treatment was better for those who were treated with CO2 laser compared to those treated with cold steel.

What this means

The study suggests that for patients who have already undergone airway procedures in the past, CO2 laser treatment may be more effective in preventing the need for repeat treatments.

If your doctor suggests using cold steel to conduct your next dilation, respectfully ask them to consider CO2 laser instead.



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What we learned

5. Endoscopic balloon dilation during pregnancy is a safe option



Reading:

“Surgical Management of Airway Stenosis During Pregnancy: A Scoping Review”

Katherine M. Miller, MD; Kevin Y. Liang, MD; Neil Nero, MLIS; Michael S. Benninger, MD; Rebecca C. Nelson, MD; William S. Tierney, MD; Robert R. Lorenz, MD, MBA; Paul C. Bryson, MD, MBA
The Laryngoscope, 134(3): 1014-1022, March 2024

<https://doi.org/10.1002/lary.30994>

This study identified 27 patients who had been treated for airway stenosis while pregnant.

The median gestational age at intervention was 28 weeks. Left lateral positioning and foetal heart rate monitoring were used in nearly every case, along with an endoscopic balloon dilation.

Jet ventilation or trans nasal humidified rapid insufflation ventilatory exchange maintained the airway.

Three women (11%) required tracheostomy prior to labour and delivery.

What this means

Treatment of airway stenosis while pregnant is safe, with careful monitoring of the foetus during the operation.

Balloon dilation is most frequently used for treatment during the third trimester.

What we learned

6. More dilation procedures prior to a cricotracheal resection (CTR) can lead to worse voice quality



Reading:

“The Impact of Previous Endoscopic Treatments on Functional Outcome After Cricotracheal Resection”

Matthias Evermann; Veronika Kranebitter; Imme Roesner; Clemens Aigner; Thomas Schweiger; Doris-Maria Denk-Linnert; Konrad Hoetzenecker
European Journal of Cardio-Thoracic Surgery, 65(6), May 2024

<https://doi.org/10.1093/ejcts/ezae105>

This study followed 65 patients post resection surgery to investigate their voice quality.

Voice-sparing resection techniques were more often possible in patients who had not previously had any dilations.

Patients who had received three or more endoscopic dilations prior to resection had more voice challenges post resection.

What this means

If you have had dilation surgeries prior to considering a resection, be aware you are likely to have some voice handicap post op.



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What we learned

7. Endoscopic tracheal reconstruction (Maddern) and airway augmentation (reconstruction with rib graft) have better voice outcomes than cricotracheal resection



Reading:

“The Voice and Swallowing Profile of Adults with Laryngotracheal Stenosis Before and After Reconstructive Surgery: A Prospective, Descriptive Observational Study”

Gemma M. Clunie; Justin W.G. Roe; Chadwan Al-Yaghchi; Caroline M. Alexander; Alison McGregor; Gurpreet Sandhu
Clinical Otolaryngology, 49(3): 324-330, May 2024

<https://doi.org/10.1111/coa.14138>

This study followed 20 patients undergoing airway reconstruction at a major centre to monitor their voice and swallowing issues both prior to surgery and afterwards.

The Maddern Procedure preserves the cricothyroid muscle, and those patients who had this procedure did not have voice changes beyond what they had previously.

Laryngotracheal reconstruction involves inserting cartilage (eg rib) into the trachea and also helps preserve voice.

Cricotracheal resection involves removal of the whole segment of cartilage and tissue where the stenosis is located.

What this means

While airway reconstruction is often ‘blamed’ for causing issues with voice and swallowing in patients, in fact this research demonstrates that often patients are struggling with these elements before their operation, and that not all reconstruction surgeries cause damage to the voice.

It supports the need for a multidisciplinary team management and consideration of voice and swallowing throughout the care pathway for airway stenosis – if you are struggling with your voice or swallowing talk to your treating doctor about a referral to a speech and language therapist.

What we learned

8. iSGS patients on the Mayo Protocol post dilation have a longer surgery-free period than those who are not



Reading:

“Impact of Procedural Variation in Endoscopic Dilation for Idiopathic Subglottic Stenosis”

Pooja Santapuram, MD; William S. Tierney, MD, MS, MS; Li-Ching Huang, PhD; Sheau-Chiann Chen, PhD; Lynn D. Berry, PhD; David O. Francis, MD, MS; Alexander Gelbard, MD
The Laryngoscope, 134(7): 3260-3266, July 2024

<https://doi.org/10.1002/lary.31393>

This research looked at how thirteen NoAAC centres treated patients with iSGS with endoscopic dilation.

Two centres stood out with patients having longer time between dilations and having higher peak flow levels for longer.

They found the key difference is the medication patients are given after dilation: proton pump inhibitor (PPI – where reflux/silent reflux is suspected), antibacterial agent (e.g. co-trimoxazole), and steroid inhaler – i.e. the Mayo Protocol

What this means

Consider asking your surgeon about starting on the Mayo Protocol for a trial period (see the relevant chapter in the Rough Guide for more information) after your next dilation surgery.

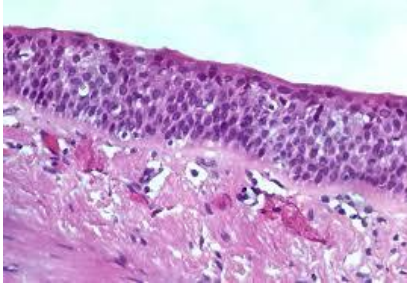


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What we learned

9. Abnormal cells found in the airways of 41% of iSGS patients



Reading:
“Idiopathic Subglottic Stenosis Is Associated with More Frequent and Abnormal Squamous Metaplasia”

Yourka D. Tchoukalova, David G. Lott, MD et al *Annals of Otology, Rhinology & Laryngology*, 133(2): 214-223, 2024
<https://doi.org/10.1177/00034894231201016>

Gene research has found seven genes have an increased expression in the subglottic tissue of iSGS patients (compared to healthy airways).

These have led to a process called squamous metaplasia – where the normal healthy airway lining becomes thicker and more like skin. This is abnormal in the airway.

The presence of these cells usually means the airway has responded to an injury – an environmental injury (eg acid, bile, cigarette smoke, alcohol) or micro-organisms (such as bacterial, viral or fungal introduction).

This could be part of the perfect storm which originated the development of the stenosis.

What this means

If a biopsy of your airway reveals these are present, you could potentially benefit from drugs aimed at reversing these cells to normal.

What we learned

10. Patients who test positive for elevated S100A8/A9 have shorter time between dilation operations



“Serum S100A8/A9 Correlates to Surgery-Free Interval in Idiopathic Subglottic Stenosis”

Maffla LM, So RJ, Abd-Elazem I, Collins SL, Chan-Li Y, Lilly G, Lina IA, Gelbard AH, Hillel AT, Motz KM.
Laryngoscope. 2024 Nov 27.
<https://doi.org/10.1002/lary.31934>

This research has found a link between elevated Serum S100A8/A9 and increased frequency of surgeries in iSGS patients.

At present this has been conducted with 20 patients. In the future this could be tested with a larger number, to hopefully cement this finding.

What this means

Testing Serum S100A8/A9 levels is done via blood sample. Serum S100A8/A9 test is not widely used in routine clinical practice but is growing in prominence in research and specialised areas related to inflammation, autoimmune diseases, and infection.

If this finding is replicated more widely, it could potentially lead to treatments which lower S100A8/A9 levels in patients which test positive for this elevation, hopefully increasing the time between dilation surgeries.



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Prepared by Catherine Anderson, founder, and administrator of the Living with iSGS support community, December 2024.



Catherine Anderson was diagnosed with idiopathic subglottic stenosis (iSGS) in 2004 following two years of misdiagnosis. Since then, she has had more than 25 procedures on her airway under a general anaesthetic, and in recent years more than 20 while awake under a local anaesthetic, receiving treatment in Australia and the UK.

Fifteen years ago, Catherine founded the group 'Living with idiopathic subglottic stenosis', on Facebook ([facebook.com/groups/airwaystenosis](https://www.facebook.com/groups/airwaystenosis)). Today there are more than 8,500 members worldwide. The community not only provides support, but is also a space to educate, share ideas, medical papers and provides a source of readily available airway stenosis subjects for further research.

She has written a free publication aimed at patients; 'The Rough Guide', which helps explain the disease, its treatments and provides advice on everyday changes to make life with airway stenosis a little easier. This has been translated into German, Dutch and Spanish.

Catherine is professionally trained in market and social research, and she marries this expertise with her understanding about airway stenosis and access to patients, working with doctors globally to conduct research which furthers knowledge about this disease and its treatments. She is an author and co-author on more than 15 published papers to date and has contributed to two book chapters.

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