# GLOBAL INITIATIVE FOR INDUCIBLE LARYNGEAL OBSTRUCTION

# GIILO STRATEGY 2024-2027

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# 1. Executive summary

- The Global Initiative for Inducible Laryngeal Obstruction (GIILO)
   association, formally established in November 2023, is an independent
   global network of individuals and organisations committed to improving
   awareness of, and care of patients with Inducible laryngeal obstruction
   (ILO).
- This initial strategy sets out four key Focus Areas for GIILO for the period 2024 -2027, which will enable the association to work towards its long-term vision to 'improve the lives of people with Inducible laryngeal obstruction.'
- The four strategic Focus Areas, each with three tangible goals to support delivery,
   are:
  - 1. Organisational Development
  - 2. Cultivating Awareness
  - 3. Accelerating Science
  - 4. Progressing Workforce
- The GIILO Executive Board will be responsible for facilitating delivery, implementing actions and monitoring impact of the strategy. The GIILO Executive Board Chair will report progress to its members annually.

### 2. Introduction

### 2.1. Context

- Inducible laryngeal obstruction (ILO) describes inappropriate, transient, reversable narrowing of the larynx, often in response to external triggers<sup>1</sup>.
   Awareness of the condition is limited: optimal management is unknown and scientific understanding is in an embryonic state.
- Healthcare professionals from across the world, working with ILO, identified the need to establish a formalised global network to progress understanding and support improved care for patients suffering with ILO.
- The Global Initiative for Inducible Laryngeal Obstruction (GIILO) was founded at the 5<sup>th</sup> International ILO Conference in Denver, USA. During its first annual general meeting (1 November 2023) a member voted Executive Board was elected, GIILO Bylaws were passed, and a GIILO association was formally established as a self-owned independent legal entity with members.
- GIILO forms an independent global network of individuals and organisations committed to improving awareness of, and care of patients with ILO.

<sup>1</sup> Halvorsen T, Walsted ES, Bucca C, Bush A, Cantarella G, Friedrich G, et al. Inducible laryngeal obstruction: an official joint European Respiratory Society and European Laryngological Society statement. The European respiratory journal. 2017;50(3):1602221-

### 2.2. GIILO vision

"To improve the lives of people with Inducible laryngeal obstruction".

### 2.3. GIILO mission

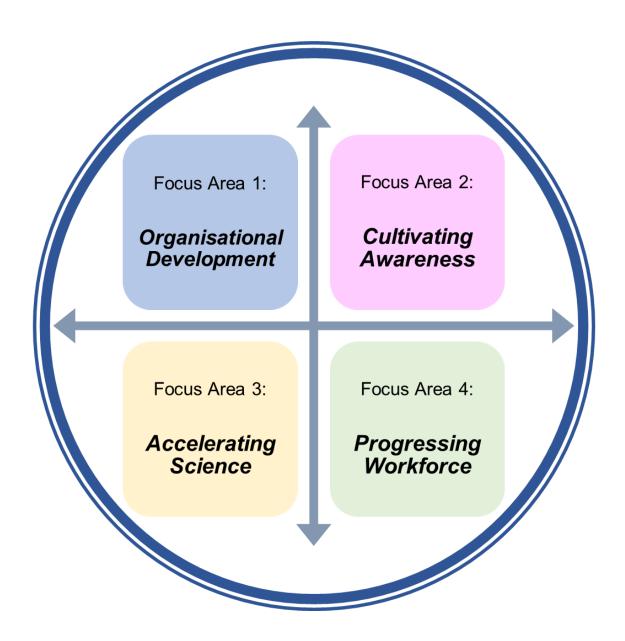
- To be recognised as a globally authoritative voice for:
  - i. influencing awareness of ILO.
  - ii. improving standards of ILO care.
  - iii. stimulating ILO research.

## 2.4. Strategy purpose

- As a newly formed association, this initial strategy aims to create a clear plan (2024-2027) to support GIILO's vision and mission.
- Specifically, the strategy's purpose is to:
  - i. provide direction.
  - ii. prioritise and focus work streams.
  - iii. assist maximising GIILO's output and impact during its inaugural years.

## 2.5. Strategy overview

- This strategy comprises four 'Focus Areas'. Each Focus Area has an overall long-term outcome, with three tangible goals to support delivery of that outcome.
- Focus Areas are not mutually exclusive. However, identifying 'Focus Areas' supports clear planning and enables identifiable workstreams, some of which maybe cross-cutting.



# 2.6. Implementation and monitoring

- In the period 2024-2027, GIILO will seek to achieve the goals set out in each Focus Area to support realisation of the long-term outcomes for organisational development, cultivating awareness, accelerating science and progressing workforce.
- The GIILO Executive Board will be responsible for facilitating delivery, implementing actions and monitoring impact of the strategy. This may include creation of member working sub-groups to support specific Focus Area goals.
- The GIILO Executive Board Chair will report annual updates to the membership, for each Focus Area, as part of the GIILO Bylaws obligations of the Annual General Meeting annual reporting.

# 3. Focus Area 1: Organisational Development

Overall long-term outcome: 'GIILO has established robust operational processes and is an association that is effective, engaging and responsive'.

- Organisational development is key to ensuring GIILO builds its capacity to change the ILO landscape and achieve greater effectiveness in delivering its vision. As a new association it is vital this is approached in a systematic way so strong organisational foundations are established.
- In the next 36 months, the following goals will be worked towards to ensure (by end of 2027) the overall long-term outcome is supported.
- The goals are:
  - To build a structure that creates capacity for action and is effectively governed.
  - 2. To develop and implement a membership attraction and engagement plan.
  - 3. To establish funding opportunities, explore income generation and set out financial governance processes.

# 4. Focus Area 2: Cultivating Awareness

Overall long-term outcome: 'GIILO proactively promotes ILO and increases awareness among healthcare professionals, health authorities and the general public'.

- Recognition and understanding of ILO varies globally among healthcare
  professionals, health authorities and the general public. This results in far
  too many patients having inaccurate, delayed or absent ILO diagnosis.
   Once diagnosed, many suffer frustration about the lack of awareness of
  their condition and the impact this has. Therefore, one of the key priorities
  for GIILO is to proactively promote ILO and support knowledge
  dissemination.
- In the next 36 months, the following goals will be worked towards to ensure (by end of 2027) the overall long-term outcome is supported.
- The goals are:
  - 1. To define, develop and manage outward facing GIILO resources, including unified messaging on website and social media campaigns.
  - 2. To develop a public and patient engagement plan that includes resources accessible in plain English.
  - 3. To actively promote GILO and work with other recognised professional bodies to cross pollinate ILO knowledge dissemination.

# 5. Focus Area 3: Accelerating Science

Overall long-term outcome: 'GILO fosters international collaborations and stimulates cohesive, prospective, fundable, research'.

- Globally, models of care are not evidence-based due to a lack of randomised data. Despite an increase in research outputs relating to ILO in the last 10 years, the majority are retrospective data and from single centres. No large multi-centre trials exist. Therefore, to support accelerated understanding of ILO, GIILO will support cohesion and collaboration to stimulate research.
- In the next 36 months, the following goals will be worked towards to ensure (by end of 2027) the overall long-term outcome is supported.
- The goals are:
  - To establish and develop a supportive GIILO incubator hub for ILO research generation.
  - 2. To develop a GILO scientific review board.
  - 3. To actively promote researcher collaborations and endorse funding applications as appropriate.

# 6. Focus Area 4: Progressing Workforce

Overall long-term outcome: 'GIILO supports the ILO workforce in education, training and development and progresses standards of care'.

- There is heterogeneity globally in the delivery of ILO care. Many clinicians
  have poor awareness and understanding of ILO and are unskilled in
  diagnostics and management. Workforce development and progression is
  a key ingredient to improve standards of ILO care.
- In the next 36 months, the following goals will be worked towards to ensure (by end of 2027) the overall long-term outcome is supported.
- The goals are:
  - 1. To support planning and delivery, annually, of a GIILO endorsed international conference to facilitate professional networking and education.
  - 2. To develop clinician resources, including webinars, to support workforce training.
  - 3. To produce GIILO professional guidelines to support the workforce in management of ILO.

# 7. GIILO 2024-2027 Strategy on a page

### **Organisational Development**

LONG-TERM OUTCOME: 'GILO has established robust operational processes and is an association that is effective, engaging and responsive'.

### Goals:

- 1. To build a structure that creates capacity for action and is effectively governed.
- 2. To develop and implement a membership attraction and engagement plan.
- 3. To establish funding opportunities, explore income generation and set out financial governance processes.

### **Cultivating Awareness**

LONG-TERM OUTCOME: 'GILO proactively promotes ILO and increases awareness among healthcare professionals, health authorities and the general public'.

### Goals:

- 1. To define, develop and manage outward facing GIILO resources, including unified messaging on website and social media campaigns.
- 2. To develop a public and patient engagement plan that includes resources accessible in plain English.
- 3. To actively promote GIILO and work with other recognised professional bodies to cross pollinate ILO knowledge dissemination.

### **Accelerating Science**

LONG-TERM OUTCOME: 'GIILO fosters international collaborations and stimulates cohesive, prospective, fundable, research'.

### Goals:

- 1. To establish and develop a supportive GIILO incubator hub for ILO research generation.
- 2. To develop a GILO scientific review board.
- 3. To actively promote researcher collaborations and endorse funding applications as appropriate.

### **Progressing Workforce**

LONG-TERM OUTCOME: 'GIILO supports the ILO workforce in education, training and development and progresses standards of care'.

### Goals:

- 1. To support planning and delivery, annually, of a GIILO endorsed international conference to facilitate professional networking and education.
- 2. To develop clinician resources, including webinars, to support workforce training.
- 3. To produce GIILO professional guidelines to support the workforce in management of ILO.

