

Elevator Pitch As Targets Communication Tools for Rare Conditions

ERN GENTURIS

European reference networks (ERN) should improve access to expert care for patients with a rare disease, accelerate research and guideline development and improve diagnostics and therapies.

Genetic tumour risk syndromes are significantly underdiagnosed and clinically complex to treat. On average only 20-30% are detected.

The ERN GENTURIS has 29 Members from 17 Member States and can be accessed from anywhere in the European Union.

Project Aim: To create a communication 'roadmap' and tools for the Network's Members to use, to improve communication about ERN GENTURIS with different stakeholders to create awareness.

ERN: Genetic Tumour Risk Syndromes Expertise Centers

ERN GENTURIS Participating Centres:

- 23 Members from 12 Member States:
 - Belgium – Ghent, Leuven & Liege
 - France – Créteil, Paris & Rouen
 - Germany – Munich, Bonn & Dresden
 - Hungary – Pécs
 - Netherlands – Nijmegen, Groningen & Rotterdam
 - Poland – Szczecin
 - Portugal – Porto
 - Slovenia – Ljubljana
 - Spain – Barcelona (x2)
 - Sweden – Stockholm
 - United Kingdom – Cambridge, Manchester & London
- 1 Supporting Partner representing 1 Member State:
 - Italy - Rome
- 7 Affiliated Partners from 5 Member States:
 - Austria - Innsbruck, Vienne
 - Denmark - Odense, Copenhagen
 - Estonia - Tartu
 - Finland - Turku
 - Latvia - Riga
 - Norway - Bergen



Stakeholder Mapping

Audience (Who)	Basic awareness of the unique needs and challenges of genetic tumour risk syndromes	Early identification & diagnosis are the critical factors to improve prognosis & access to in-time treatments	Genturis syndromes are underdiagnosed and clinically complex to treat	Genetic tumours are hereditary, so always think beyond the patients	ERN GENTURIS has an important value as a network focused on prevention of cancer	ERN GENTURIS expertise and services available	Other
European Commission, Council & Parliament (1)	✓				✓		✓ Understanding of the specific needs and challenges of GENTURIS conditions.
ERN Board of Member State & Ministry of Health (2)	✓	✓			✓		
Clinical Community & Hospital Exe (3)	✓	✓	✓	✓		✓	
Patient Community – National & European & General Public (4)	✓	✓	✓	✓	✓		✓
Other European Reference Networks Community (5)				✓	✓		
Potential New HCP Members & Affiliated Partners (6)		✓				✓	
Medical Tec. & Pharmaceutical Industry (7)		✓				✓	

Method

The Network identified and prioritised the key messages.

In small groups of 3-4 people, develop an 'elevator pitch' that is no longer that 60 seconds! Each group focused on different stakeholder groups.

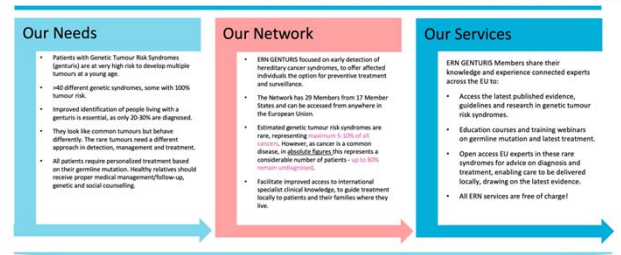
Each 'pitch' must be memorable and have IMPACT and each message be tailor to different to different audience:

- European Commission, Council & Parliament
- ERN Board of Member State & Ministry of Health
- Clinical community & hospital executives
- Patient community
- Other European Reference Network
- Potential New HCP Members & Affiliated Partners

Results - Key Messages

- ERN GENTURIS is a Network at the EU level, helping to set and deliver standards of care for patients and their families with a hereditary form of cancer.
- Early detection of these genetic tumour risk syndromes is critical, as there is increased risk of morbidity and/or cancer and can affect the whole family.
- Offer the highest potential of prevention, early detection and proactive management that can significantly improve prognosis and lives.
- The specific needs of these patients are not addressed by the routine care available in the EU.
- With more hereditary cancer centres ERN GENTURIS will make preventative oncology possible.
- Working together, early detection improves prognosis, enabling access to in-time treatments and save lives.
- Remember, if you think it's rare, think genturis. If it is hereditary, then think of the whole family!

ERN GENTURIS COMMUNICATION ROADMAP



- Key Messages:**
- ERN GENTURIS is a Network at the EU level, helping to set and deliver standards of care for patients and their families with a hereditary form of cancer.
 - Early detection of these genetic tumour risk syndromes is critical, as there is increased risk of morbidity and/or cancer and can affect the whole family.
 - Offer the highest potential of prevention, early detection and proactive management that can significantly improve prognosis and lives.
 - The specific needs of these patients are not addressed by the routine care available in the EU.
 - With more hereditary cancer centres ERN GENTURIS will make preventative oncology possible.
 - Working together, early detection improves prognosis, enabling access to in-time treatments and save lives.
 - Remember, if you think it's rare, think genturis! If it is hereditary, then think of the whole family.

Your local ERN GENTURIS Members and the latest ERN guidelines can be found on the website - www.genturis.eu

Conclusion:

- Elevator pitches provide a valuable tool in creating awareness by targeted short messages for different audiences.
- Messages may need to be adapted each year as the narrative around ERN GENTURIS starts to mature.

