

# Holistic psycho-social support for people living with a rare disease and their family members

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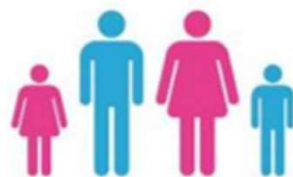
# What is a Rare Disease ?

OVER  
**6000**

distinct rare  
diseases

Each one affects  
fewer than

**1 IN  
2000  
PEOPLE**



All together, an  
estimated

**30  
MILLION PEOPLE**

are living with a rare  
disease in Europe



**Expertise, knowledge,  
information** on diseases and  
their consequences are **scarce**  
and difficult to access



**Rare, complex, chronic,  
disabling, progressive,  
degenerative, often  
life-threatening**

**NO  
CURE** 

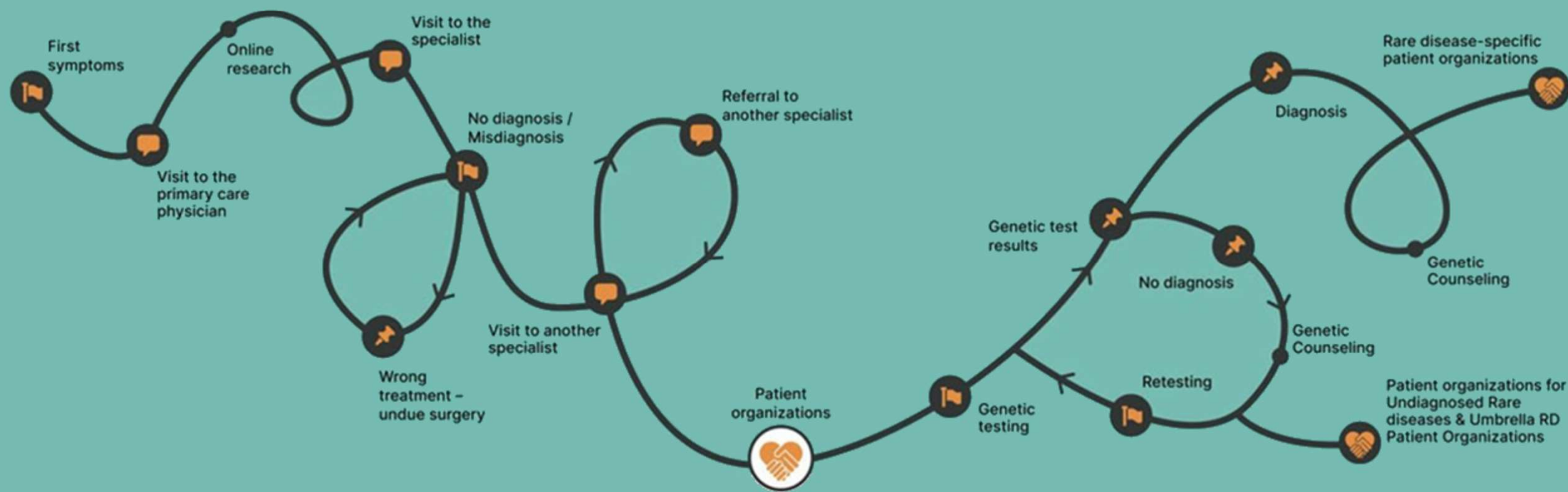
for the vast  
majority of  
diseases and  
few treatments  
available

They are **geographically  
scattered** and often  
**isolated**

**Few experts,  
geographically scattered**  
**Research is fragmented**

# The impact of rare diseases on daily life and well-being

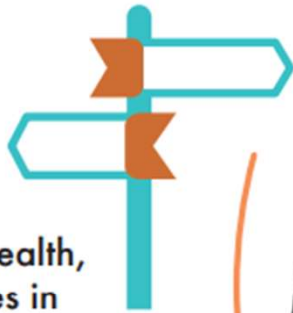
# Patient Journey through diagnosis



# Serious care burden for PLWRD & carers

**65%**

have to visit different health, social and local services in a short period of time



**67%**

feel that these services communicate badly between each other



**7in10**

do not feel well informed about their rights



**7in10**

find that organising care is time-consuming; 6 in 10 find it hard to manage





**85%**

**OF PEOPLE LIVING  
WITH RARE DISEASES  
REPORT THAT THEIR CONDITION  
AFFECTS THEIR PHYSICAL AND  
MENTAL HEALTH.**

RARE BAROMETER SURVEY 2017

#RAREDISEASEDAY  
RAREDISEASEDAY.ORG

29 FEB  
2024

# Psycho-social support

Reduces stress, burden and isolation among  
PLWRD & care givers

Nunn, R. "It's not all in my head!" - The complex relationship between rare diseases and mental health problems. *Orphanet J Rare Dis* **12**, 29 (2017). <https://doi.org/10.1186/s13023-017-0591-7>

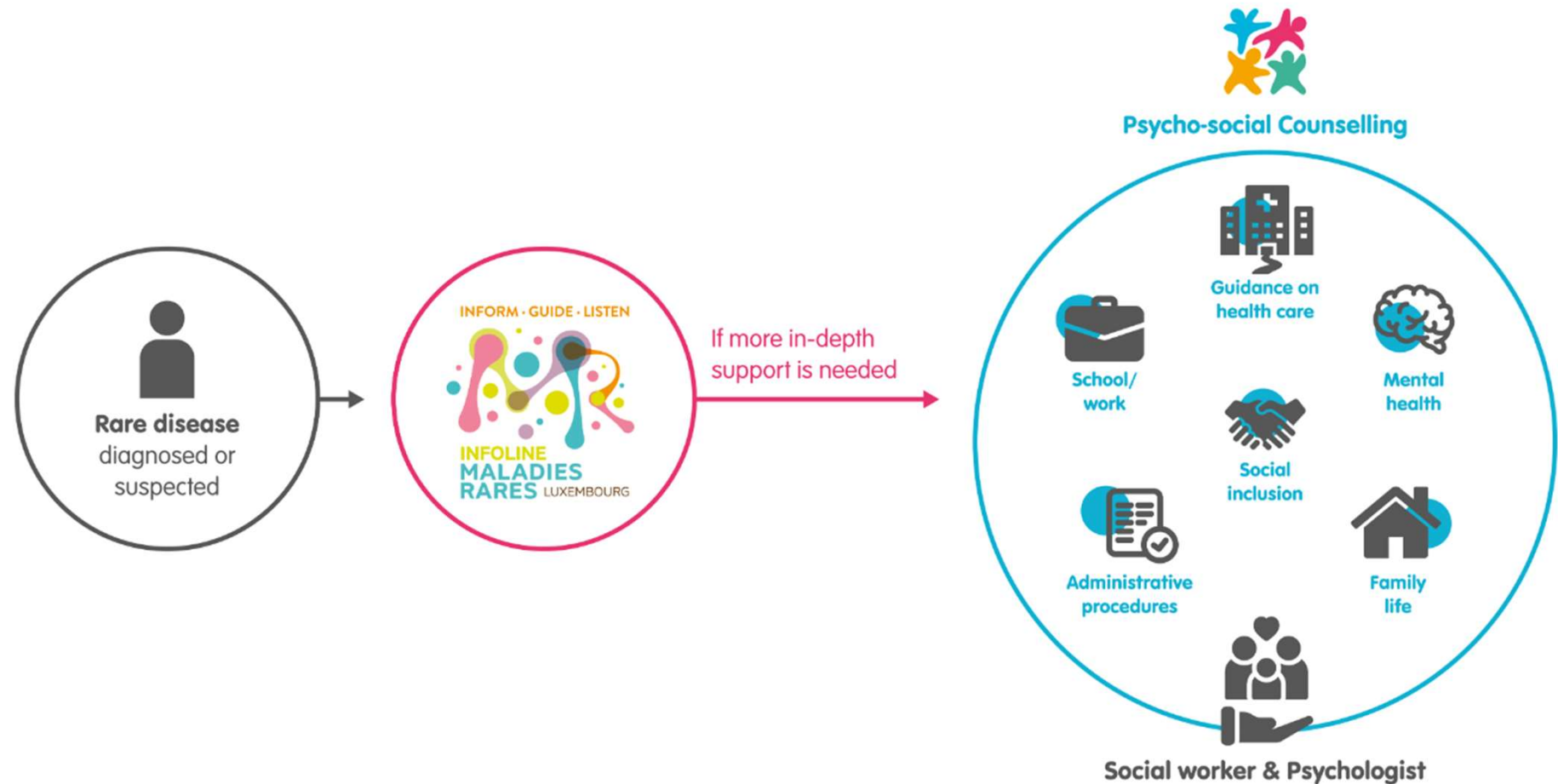


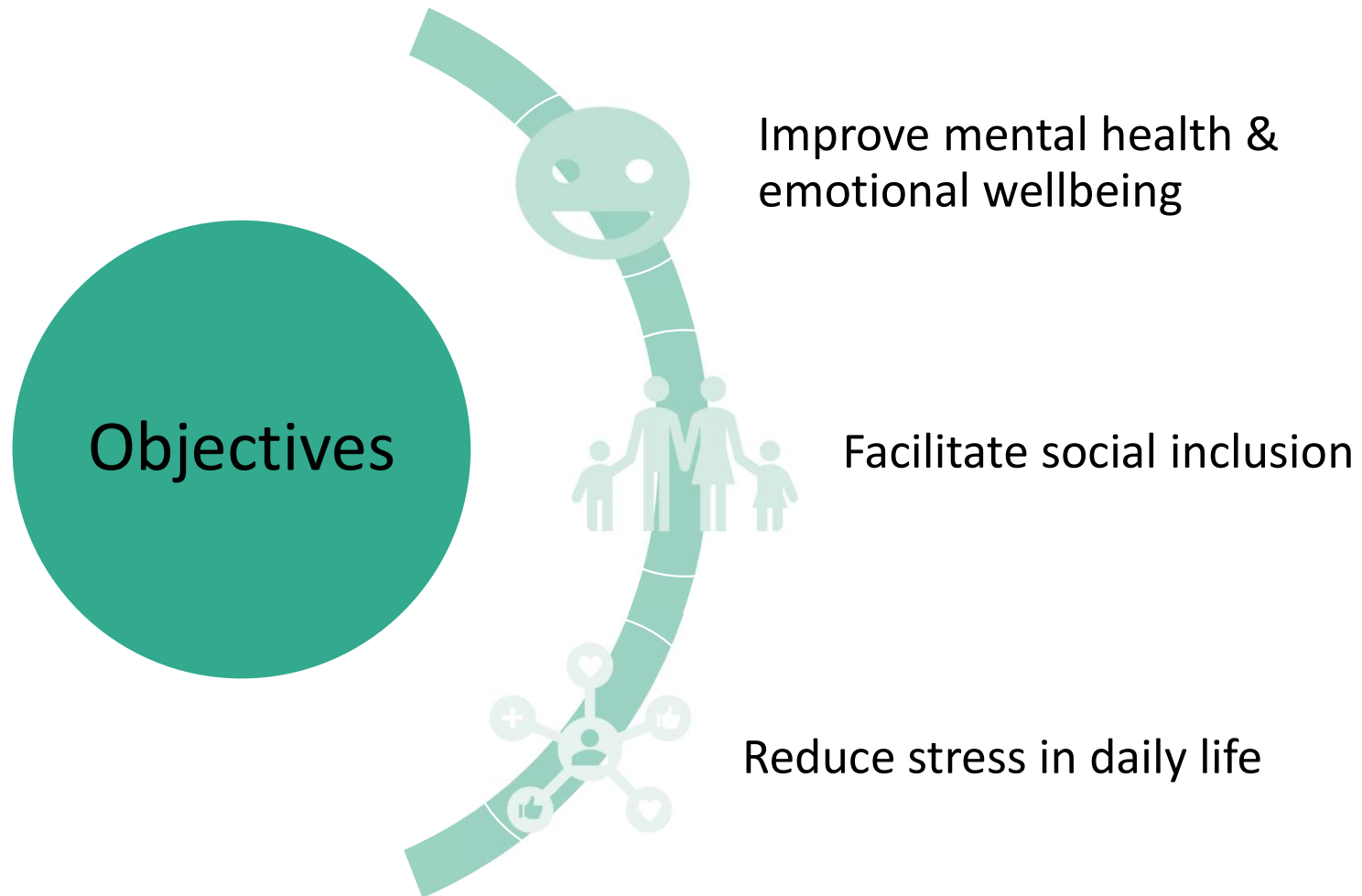
# General aims of psycho-social support

- ✓ **Overcome their care burden and to secure the services and support that they require**
- ✓ **Achieve a quality of life on an equal footing with other citizens**
- ✓ **Participate in society and in the job market to their highest potential**
- ✓ **Fully realise their fundamental human rights**

INNOCare

# ALAN's consultation service





# Pathway



Request via Infoline



First consultation with  
psychologist & social worker



Co-creation of support plan

# Pathway



# Pathway





# Challenges

Coordination within  
the team

Cultural differences

Inclusion criteria

Staying up to date

Prioritization of  
requests

Navigate the system

# Countering these challenges

## Communication

- Weekly team meetings
- Custom-made, secure database
- Documenting all interventions

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## Team support

- Intervisions between team members
- Monthly supervisions with external expert
- Continuous training
- Caring leadership

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## Team attitude

- Respect & empathy
- Cooperation & trust
- Focus on patient goals

# Breaking down conventional barriers

- ✓ Service is **free of charge**
- ✓ **Multilingual** (important in Luxembourg)
- ✓ **Respect** for different cultural backgrounds and believe systems
- ✓ **Patient-centered** and **needs based** approach
- ✓ **Accessible** office space
- ✓ **Staff specialized in rare diseases**
- ✓ Good **visibility** and reputation

# Reach of our Service

Luxembourg



2586 km<sup>2</sup>



# Policy Context

The National Plan on rare diseases allowed us to:

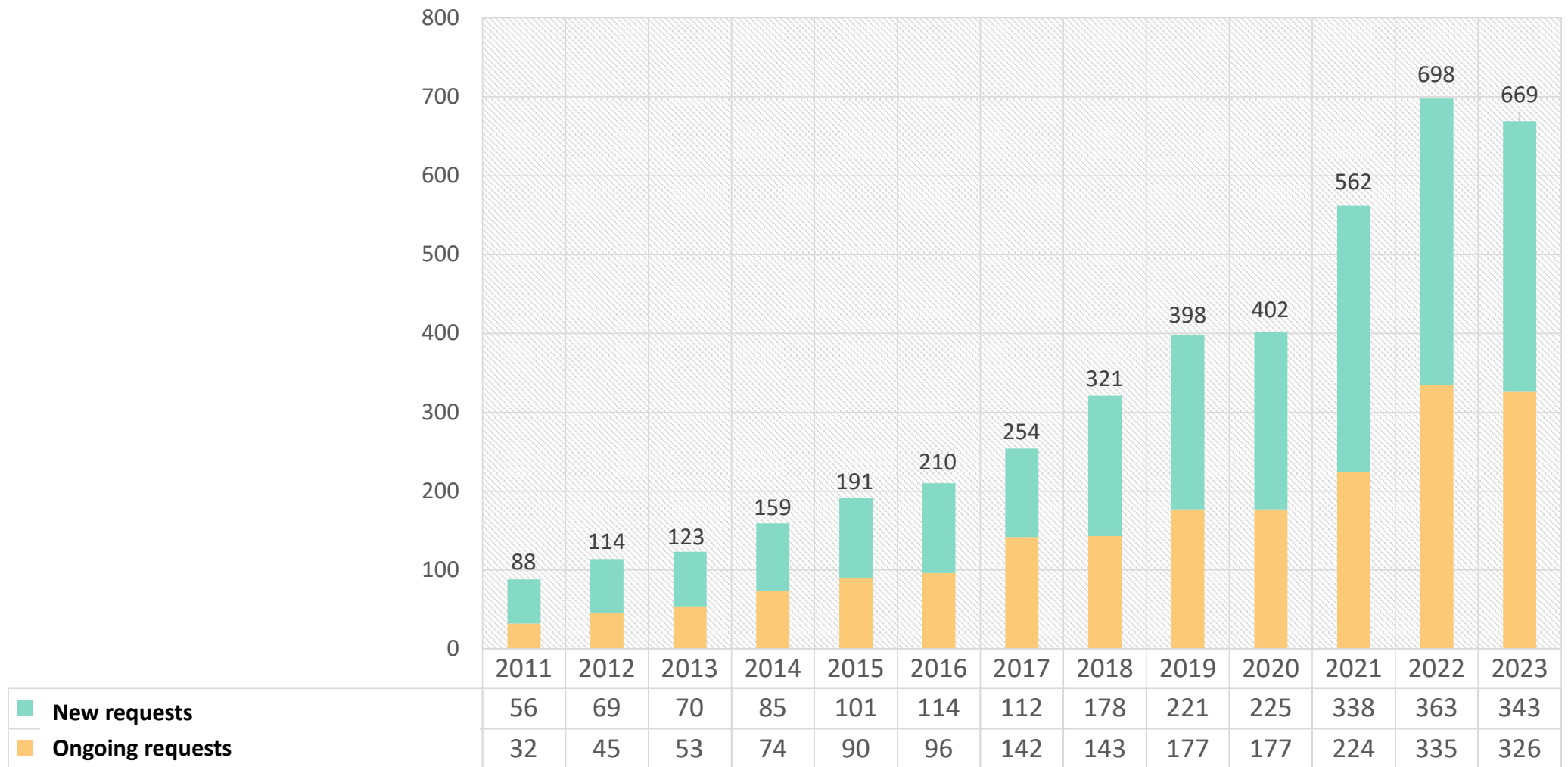
- ✓ Create the National Rare Disease Infoline
- ✓ Hire more staff
- ✓ Further professionalize
- ✓ Increase our visibility



PLAN NATIONAL  
**MALADIES  
RARES**  
LUXEMBOURG

2018 2022

# Number of requests for support



# Reach of our Service in 2023



140 Psycho-social consultations



114 Social consultations



901 Psychological consultations



115 Interdisciplinary meetings



31 Accompanied medical visits



11 Other

# Practicalities & Transferability



5 social workers  
& 3 psychologists



Personal office  
space



2 consultation  
rooms



Access free  
building



2 company cars



Training budget

# Contact

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