

# SESSION 10

## QUALITY OF LIFE

# QUALITY OF LIFE GROUP

Comprehensive Group presentation :

Parents, patients, social worker, doctors,  
scientist, anthropologist, hospice carer :

**Mostly Affected**

1)What does Quality of Life mean to Us?

2)What are the GAPS to achieve QOL ?

3)Goals to achieve QOL for RD

# 1)What does Quality of Life mean to Us?

- Very individual views, very different values of “life”
- 2 Groups : The artists and the pragmatists – a drawing and a list

# Quality of Life for RD

Many different things – and Mismatch  
between HCP and patient perception

Family and community are all affected

Important to find what is your meaning and  
purpose in this life

# Individual comments

- “Mindfulness” and live it !
- Not being defined by his/her RD condition.
- Being comfortable with oneself
- Having access to resources
- Being painfree or having balance of pain
- Having autonomy , independence including an advanced health care plan.

- Continue dreaming and have “ the party “
- To have love, warmth, support, “step out into the sun “
- Being allowed to define one’s own happiness – as long as he/she smiles !
- Getting to maximum individual potential
- Having energy and maintain will and desires.
- Capture the “special moments” – camera, video..
- Be aware of different perceptions of youth for their changing needs regarding QOL

# What are the GAPS to achieve QOL ?

- Multidisciplinary teams needed, collaboration
- Rare diseases needs special clinics at dedicated centres
- Need passion to have integrated systems
- Need paediatric palliative care
- Lack of choice – needs to be addressed to access the specific knowledge/person
- Empowerment of other healthcare professionals and PARENTS  
Parents if they know more – need to be heard and represented but also not forced to take responsibility
- Patients need to be present at Congresses as professionals



# Goals to achieve for QOL

Thrive not survive!

- RARE-X starts with basic definitions, hereafter more individualized meetings with defined priorities needed :
  - Future representation at congresses as professionals
  - Patient organized congresses
  - Develop effective patient virtual Communication Networks

# On more individual/hospital level

- See how patient redefines his family and his surrounding society – and how it can be normalized especially in extended family : -Discuss  
realistic home plan  
-Care Plan for individual patients with “police stamp” if needed  
-Palliative Care Plans
- Specialized Rare Disease Clinics and networks
  - Shared healthcare with patients/parents promotes reduced malpractice
  - Become involved in Ethics of diagnosis and treatment and promote, including ethics review boards at treating institutions