New Advocate Topic: Rare Diseases & Mental Health
• Mental health is now being recognized as a public health priority in the European Union, notably in Commission President von der Leyen’s State of the Union speech at the European Parliament on the 14 September 2022, it is imperative that rare diseases are seen as a vulnerable population requiring specific attention in the new EU Action Plan on Mental Health to be presented in June 2023.

• Rare diseases are complex multi-system conditions requiring a holistic approach to meet their health and psycho-social related needs. For many rare diseases, mental health, learning disability and behavioural challenges are common associated co-morbidities.

• The rare disease patient community have highlighted the increased psychological impact and the associated mental, learning and behavioural co-morbidities as being a significant and debilitating unmet need affected not only the PLWRD but also the family and caregivers.
Rare Diseases & Mental Health

Psychological Impact along the Patient Journey:

- Undiagnosed disease and impact of the diagnostic odyssey
- At diagnosis
- Living with a Rare Disease (groupings of common characteristics):
  - Functional Impairment (BBS, Rare Epilepsies, RETT)
  - Progressive diseases (MND, SMA)
  - Visible disabilities (NF1, Craniofacial Anomalies)
  - Surveillance (Genetic Tumours Risk Syndromes; Rare Cancers)

Risk Factors to Mental Wellbeing through increase complexity, rarity, progression, prognosis, visible and invisible disabilities:

- Isolation
- Digitalization
- Age and gender inequalities
- Impacting on education work and independent living
- Reduced economic capacities

MH affecting the person living with a rare disease & the wider family – partner, parents, siblings and carers
Objectives

Short-term objectives: For people living with a rare disease, and their family and carer givers, to be:

- **Recognized as a vulnerable group** with a higher risk of develop symptoms of mental disorders and associated increased psychological impact to be included in education, work and society.
- Included in the new EU Action Plan on Mental Health to address unmet needs of people living with a rare disease and their families/relatives/carers, across a wide range of rare diseases and across countries.

Long-term objectives:

- The **psychological health** of people affected by rare diseases are considered at each stage of their life journey
- The **simple effective social and psycho-social interventions** are implemented to prevent the costly down stream health system impacts of unmanaged psychological burdens.
Gathering Evidence

Call to National Alliances, and your Members, for evidence on rare diseases and mental health:

- Please share any publications, surveys, workshop reports
- Send to matt.johnson@eurordis.org

Call for leads from National Alliances who have been active in MH

*Deadline: end of January 2023 (preferrable earlier)*
New EURORDIS Mental Health Advocates Network

EURORDIS Board supports the need to implement a specific strategy on mental health and wellbeing for people living with a rare disease, their family and caregivers to achieve the following objectives:

- Support and reinforce a united and empowered rare disease community affected by mental health to come together and be seen, learn and supported each other;

- Better support and integrate mental health in the all policy areas and initiatives carried out by EURORDIS for all rare diseases;

- Help increase visibility of the psychological impact and associated co-morbidities of mental health, learning difficulties and behavioural disorders in:
  - the world of rare diseases and rare cancers
  - the world of mental health
Timeline and milestones – Q1-2 2023

January
- Gathering Evidence with CNA
- Review EURORDIS Surveys
- Targeted Literature Reviews
- Joint MHE Advocacy Platform

Mid January to Mid February
- EC Call for Evidence

End of January
- Draft Paper & Recommendations on RD & MH

March & April
- Continue building the evidence base

May
- EURORDIS Membership Meeting
- Call for Advocates to join new MH Advocates Network

Beginning June
- EC publish Commission Communication & Action Plan on Mental Health
- Policy Event

May
- Launch new EURORDIS MH Advocates Network
Rare Diseases & Mental Health

PLWRD are exposed to increased inequalities due to the intersections between living with a rare disease, disability and mental health disorder, that impact on all aspects of daily lives and affect the ability to earn a living and live independently and affecting their ability to be active participant in education, work and society.

• Rare disease of often diagnosed late and after many delays. Impact of the diagnostic odyssey.

• Progression of disease, living with a visible disabilities, functional impairment and poor prognosis and the impact due to ongoing surveillance.

• Receiving a definitive diagnosis, parents often feel initial relief, which is soon replaced by overwhelming feelings of stress and guilt, that manifests through a range of psychological symptoms.