The Impact of Rare Diseases on Mental Wellbeing

Webinar, 13.06.2023
Welcome!
We will be starting shortly...

- Mute your microphones when not speaking
- Turn on your camera, if possible – it’s nice to see your face!
- Use a headset or earphones to minimize echo and background noise
- Add your name – in the ‘Participants’ list, on your name click and ‘Rename’
- Raise your hand if you wish to speak & use chat box for Q&A and comments

Webinar will be recorded
Welcome & Opening Remarks

Iris, Ehlers-Danlos syndrome, chronic paroxysmal hemicrania, cluster headaches
Unseen and neglected unmet need that is frequently overshadowed by the other medical complexities.

Increased exposure to social inequalities and discrimination.

Increase risk factors for poor mental health.

PLWRD can have associated mental health co-morbidities.

Community live with the increased psychological impact associated with the rare diseases journey across all stages of life.

Look beyond the physiological symptoms of a rare disease and take action to address the psychological impact associated with rare diseases.
Webinar aims to build understanding about mental health and explore the impact of rare conditions on mental wellbeing in all aspects of daily lives.

Also to identify concrete policy actions that can be taken to address these needs.

Finally, to stock of EU Actions being taken under the new Communication and share the advocacy work EURORDIS is leading on in Mental Health.
Webinar Speakers

Fatima Awil
Policy and Knowledge Officer
Mental Health Europe

Kym Winter
Founder & Clinical Director
Rare Minds

Avril Daly
Retina International
President OF EURORDIS

Tom Kenny
Chief Executive Officer
Rare Disease Research Partners

Matt Bolz-Johnson
Mental Wellbeing Lead
EURORDIS
<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Speaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>15.00 – 15.05</td>
<td>Welcome &amp; Opening Remarks</td>
<td>Avril Daly, Retina International &amp; EURORDIS</td>
</tr>
<tr>
<td>15.05 – 15.25</td>
<td>Defining Mental Health &amp; Europe - Response to addressing the Public Health Priority</td>
<td>Fatima Awil, Mental Health Europe</td>
</tr>
<tr>
<td>15.25 – 15.40</td>
<td>Impact of Mental Wellbeing on Rare Diseases</td>
<td>Kym Winter, Rare Minds</td>
</tr>
<tr>
<td>15.40 – 15.55</td>
<td>Psychological support at diagnosis for a Rare Disease</td>
<td>Tom Kenny, Rare Diseases Research Partners</td>
</tr>
<tr>
<td>15.55 – 16.15</td>
<td>Panel Q&amp;A</td>
<td>Matt Bolz-Johnson, EURORDIS</td>
</tr>
<tr>
<td>16.15 – 16.25</td>
<td>EURORDIS advocacy activity &amp; the new Mental Wellbeing Partnership Network</td>
<td>Matt Bolz-Johnson, EURORDIS</td>
</tr>
<tr>
<td>16.25 – 16.30</td>
<td>Closing Remarks &amp; Next Steps</td>
<td>Avril Daly, Retina International &amp; EURORDIS</td>
</tr>
</tbody>
</table>
Defining Mental Health & Europe - Response to addressing the Public Health Priority

Fatima Awil, Mental Health Europe
The World Health Organisation (WHO) defines mental health as “a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.”

- Mental health is an integral component of health and well-being and impacts our collective abilities to:
  - make decisions
  - build relationships
  - shape the world we live in.
Factors can increase or decrease our likelihood of experiencing mental health problems.

**Risk Factors**
- Expected & unexpected life circumstances
- Poverty
- Lack of social support
- Substance abuse
- Traumatic Event
- Early childhood lack of care
- Bullying

**Protective Factors**
- Positive norms
- Opportunities to pursue interests
- Good support system
- Physical health
- Physical and psychological safety
- Social relationships
United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)

- UN CRPD is a human rights treaty for persons with disabilities.
- The UN CRPD protects and promotes the rights of persons with disabilities.
- This binding United Nations document was signed and ratified (basically approved or agreed) by the EU Member states and the EU!

The UN CRPD has changed the way we understand psychosocial disability = Paradigm Shift
biomedical model → a psychosocial model of mental health
EU Action on Mental Health

- EU-Compass for action on mental health and well-being
- European Pact for Mental Health and Well-being (2008)
- Council Conclusions on a “European Pact for Mental Health and Well-being: results and future action”
- Council Conclusions on the Economy of Well-being (December 2019)
- Position Papers by Political Groups – Renew, S&D Group
- INI REPORT on mental health in the digital world of work (2021/2098(INI))
- EU Health Policy Platform – “COVID-19: Mental Health Support” network
- EU ‘Healthier Together’ initiative
- Health Policy Platform Mental Health in all Policies Thematic Network
- European Commission Communication - A comprehensive approach to mental health (2023)
- INI Report on mental health (upcoming)
European Commission Communication - A comprehensive approach to mental health

The key priorities include:

1. Integrating mental health across policies
2. Promoting good mental health, prevention and early intervention for mental health problems
3. Boosting the mental health of children and young people
4. **Helping those most in need**
5. Tackling psychosocial risks at work
6. Reinforcing mental health systems and improving access to treatment and care

MHE considers the Communication on a comprehensive approach to mental health as an essential first step, laying the foundation for a stronger commitment to mental health in the future.
Strengthening prevention and support for mental health across EU countries

- Cross-sectoral collaboration and strengthening integrated social and healthcare
- Promote and invest in basic social rights and in economic protection packages
- Increase awareness & reduce the stigma associated with mental health problems
- Promote and support community-based services
- Adopt comprehensive long-term strategies
- Shift in culture
Impact on Mental Wellbeing of Rare Diseases

Kym Winter, Rareminds
Mission & Vision

Our vision is that the psychological and emotional aspects of living with a rare condition are recognised as an integral part of rare disease care, with access to specialist quality services for all.

Our mission is to provide affordable, timely access to highly specialised counselling for the rare disease community, and campaign for recognition of the importance of specialist mental health support by informing policy, practice and promoting standards of excellence.
# What We Do

## Service Provision
- Couples/individual counselling.
- Group programmes.
- Workshops.
- Self-help psycho-educational resources.

## Training & Support
- Clinical supervision for front-line workers.
- Rare leader training, group supervision & consultancy.
- Workshops, training & courses for HCP.
- Partnership working.

## Research & Awareness
- Presenting at conferences, stakeholder, partners & industry events.
- Contributing case studies & expert opinion.
- Build data - initiating & contributing to research.
- Inform policy and practice.

---

![Rare Minds](https://example.com/rare-minds-logo)

*Rare Minds*
Mental Health for the Rare Disease Community
Mental Health: The Missing Piece

Mental health is increasingly being recognized as the ‘missing piece’ in rare disease care......

“People living with rare diseases and their families often have very specific needs for mental health support ...this needs to be well coordinated with their wider health and social care.”
England Rare Diseases Action Plan (2022)

“Living with a rare disease has a substantial impact on mental health...many drivers of poor mental health reflect issues that are specific to managing a condition that is rare”
Mental health care for rare disease in the UK: recommendations Spencer-Tansley et al BMC Health Services Research 2022 (p12)

“Patients feel the average therapist doesn’t understand the specific needs of rare disease patients”
Patient Insights Across Rare Diseases' Lumanity White Paper (April 2022)

“Being affected by a rare disease has a huge impact on mental health”
Juggling Care and Daily Life: EURORDIS Rare Barometer Survey (2017)
Rare Disease Mental Health Stressors

Lengthy/traumatic diagnosis
> Reduced trust in HCP’s

Complex interacting emotional and physical symptoms

Multiple uncertainties
> anxiety

Low disease awareness among professionals / public
> Isolation, frustration

Emotional impact of symptoms, ttmts, monitoring
> Trauma

Stress and strain on family life / couple relationships

High logistical burden of disease/care management

The impact of genetic inheritance on identity, and life choices
> Grief and loss

rareminds
Mental Health for the Rare Disease Community
Impact on Mental Health

Rare Disease UK Report (2018)

95% have felt worried or anxious
93% have felt stressed
90% have felt low
88% have felt emotionally exhausted
70% have felt at breaking point
36% patients / 19% carers experienced suicidal thoughts

48% parent-carers not asked about their child’s MH

46% patients/ 57% carers had never been asked about their mental health and wellbeing.
Biopsychosocial Approach

**Biological**
- Genetics
- Medication
- Neuropsychiatry
- Hormones
- Metabolism
- Immune responses
- Common health morbidities

**Socio-environmental**
- Peers
- Socio-economic factors
- Access to health/social care
- Family
- Climate crisis
- Religion
- Digital tech
- Culture
- Education
- Work

**Psychological**
- Personality
- Learnt responses
- Cognitive capacity
- Emotions
- Stress

**Mental Health**
- Diagnostic odyssey
- Disease awareness
- Uncertainty
- Grief & loss
- Trauma

**Self esteem**
- Coping strategies
- Social skills
- Beliefs & attributes
- Personal ascription of ‘meaning’
There Is No Health Without Mental Health

The relationship between physical and mental health is well established

- Poor mental health > can impact on physical health, the capacity to selfcare, resilience etc.
- Poor physical health > higher rates of depression, anxiety etc.

www.mentalhealth.org.uk/explore-mental-health/mental-health-statistics/physical-health-conditions-statistics
So what is needed?
1. Mental health support must be proactive, preventative and responsive

⇒ Monitoring and assessment of mental health and wellbeing must be integrated and normalized into rare disease care.

⇒ Early support and intervention at the point of felt need mitigates distress, and prevents difficulties escalating and entrenching.

⇒ Support to extend across the rare disease journey (pre-diagnosis and beyond).

⇒ Systemic difficulties contribute significantly to stress/distress and consequential mental health difficulties.
2. Support for mental health and wellbeing is not ‘one thing’ and one size does not fit all

It must be:

⇒ Tailored to take into account the impact of that condition.
⇒ The needs/preference of the individual.
⇒ Requires creative, ‘joined up working’
3. Mental health support and assessment of needs must become integrated into ordinary rare disease care

⇒ Train physical healthcare practitioners to become more ‘psychologically aware’ > ‘psychologically informed’ medical care

⇒ Train mental health care practitioners to become more ‘rare aware’ > ‘rare-informed’ mental health care

Mental health aspects of care must not be ‘bolted on’ as an afterthought

A robust holistic approach includes:

⇒ Support for mental wellbeing/health of caregivers

⇒ Support for PAGS (especially frontline support staff and volunteers)
And finally!

⇒ Opportunity to learn from (good) practice for long term conditions, cancers, the pandemic etc

⇒ Urgent need to train clinicians (medical and psychological) to think creatively and collaboratively with respect to mental health and wellbeing

⇒ Recommendations must be rooted in a partnerships between lived experience and professional expertise

⇒ Mental health has always been the ‘poor relation’ to physical health, and rare disease mental health support must not be ‘the crumbs from the table’

Let's do it better for rare conditions 😊
‘Rare Minds Matter’

Mental health support must be an integral part of rare disease care.

**Survey:** If based in the UK, please complete our survey:

Our **‘Rare Minds Matter’ Campaign** launching late 2023 / early 2024.

Our **CPD module for HCPS** in partnership with Medics for Rare Diseases on ‘Mental Health and Rare Diseases’ (launching summer 2023).
www.rareminds.org

Thank you
Psychological support at diagnosis for a Rare Disease

Tom Kenny, Rare Disease Research Partners
WHAT THE PROJECT INVOLVED

A systematic literature review
Relevant articles sourced using the electronic database PubMed, and reference listing.

Development of a Statement of Good Practice
Raising awareness and providing guidance for healthcare and other supporting professionals and organisations.
A REVIEW OF THE LITERATURE

IDENTIFICATION

References from databases
n = 724

SCREENING

Total papers found
n = 1274

RESULTS

Hand searched references
n = 550

Articles excluded due to topic not relevant, abstract or text not available
n = 1239

Papers included
n = 35
### Key Findings – Detrimental

- Delayed diagnosis sets up a complex emotional state
- Poor diagnostic delivery
- Lack of information immediately after diagnosis
- Lack of specialist knowledge from their healthcare professional
- Lack of psychological support or counselling at the time of diagnosis
- Maze-like healthcare systems
- Ignored practical needs
- Forgotten family members
### Key Findings - Supportive

- A definitive diagnosis
- Provision of managed information
- Assessing psychological risk factors
- Developing support systems
- Guidance of health system navigators
- Teaching coping techniques
- Specific psychological and psycho-social interventions
Statement of Good Practice

Overview

10 recommendation across 5 areas:

- Delivery of the Diagnosis
- Curated Information
- Access to Expertise
- Access to a Psychological Practitioner
- Single Co-ordinating Professional
Strength of recommendation

Evidence to support the recommendations have been graded using the following definitions:

- **Strong evidence**: consistent evidence and new evidence unlikely to change recommendation and expert consensus

- **Moderate evidence**: expert consensus or majority decision but with inconsistent evidence or significant new evidence expected

- **Weak evidence**: inconsistent evidence AND limited expert agreement
# Delivery of the Diagnosis

**Delivery of the Diagnosis**

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Grading</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Diagnosis should be delivered by a health professional with substantial</td>
<td>Strong</td>
</tr>
<tr>
<td>knowledge of the condition and with training in how to deliver difficult</td>
<td></td>
</tr>
<tr>
<td>news</td>
<td></td>
</tr>
<tr>
<td>2. The healthcare professional should allow sufficient uninterrupted time to</td>
<td>Strong</td>
</tr>
<tr>
<td>deliver the diagnosis in a sensitive and unhurried manner, allowing for the</td>
<td></td>
</tr>
<tr>
<td>information to be processed</td>
<td></td>
</tr>
<tr>
<td>3. When more than one professional is involved in delivering the diagnosis,</td>
<td>Moderate</td>
</tr>
<tr>
<td>all professionals should remain with the family throughout the entire consultation</td>
<td></td>
</tr>
<tr>
<td>4. A private, comfortable, quiet space with room for the family, and all the</td>
<td>Moderate</td>
</tr>
<tr>
<td>healthcare professionals involved to remain during the diagnosis should be</td>
<td></td>
</tr>
<tr>
<td>provided</td>
<td></td>
</tr>
</tbody>
</table>
**Curated Information**

*A reliable source of curated information*

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Grading</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Parents and caregivers should have access to a source of accurate information that is frequently and regularly reviewed and updated so it remains relevant and useful</td>
<td>Strong</td>
</tr>
<tr>
<td>2. Signposting for parents and caregivers to relevant and accessible financial and mental health support services</td>
<td>Weak</td>
</tr>
</tbody>
</table>
## Access to Expertise

### Access to expertise

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Grading</th>
</tr>
</thead>
<tbody>
<tr>
<td>No single source alone can support the information needs of families affected by rare and complex diseases. Information needs contextualisation and interpretation to become useful knowledge. This interpretation and contextualisation are best done by people with substantial experience, knowledge and expertise surrounding the care, impact and prognosis of a given disease.</td>
<td>Strong</td>
</tr>
<tr>
<td>Recommendations</td>
<td>Grading</td>
</tr>
<tr>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>---------</td>
</tr>
<tr>
<td>1. Psychological assessment and support delivered by a trained, experienced healthcare practitioner should be readily available to all families from the time of diagnosis onwards</td>
<td>Strong</td>
</tr>
</tbody>
</table>
# Single Co-ordinating Professional

A single (or named) professional with clear responsibility for co-ordination of care

## Recommendations

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1.</strong></td>
<td>Most health systems have a professional (e.g., General Practitioner) who implicitly or explicitly co-ordinates care. In rare and complex disease, that professional needs additional support to gain sufficient disease and service knowledge to effectively co-ordinate care</td>
</tr>
<tr>
<td><strong>2.</strong></td>
<td>Experts need to actively share disease knowledge with the co-ordinating professional</td>
</tr>
</tbody>
</table>
Thank you
Q&A and Panel Discussion

Iris, Ehlers-Danlos syndrome, chronic paroxysmal hemicrania, cluster headaches
Kacper from Poland is living with Kawasaki disease

EURORDIS
Advocacy Action
Living with loss
- Rare disease journey is played out on the background of grieving for the loss of the lives and future/dreams you had. Stages of grief include trauma, grief, denial, depression and acceptance.

Survival mode:
- Hyper alert and increased accumulated and sustained stress, fears and worries due to living in uncertainties about the outcomes/future/impact for a protected period.

Delaying with uncertainty and unpredictable events:
- Impact of lack of coordination, inform can quickly change and an unpredictable events increases the trauma (PSTD).
- Poor communication and handling of a diagnosis casts a long shadow across the future journey due to lost of trust.

Breaking down stigma:
- Stigma creates an unnecessary extra burden for PLWRD and their families.
New EURORDIS Mental Wellbeing Partnership Network

Support and reinforce a united and empowered rare disease community affected by mental wellbeing ...

... to come together and be seen, learn, advocate and supported each other.
Terms of Reference

**Mission:** Harness the collective evidence, innovations, best practices, tools and resources, and level up the capacities to shape policies and promote practices that reduce the impact of rare diseases on mental health.

**Structure:** Steering Committee & Working Groups

**Meetings:** Network will meet x3 per year

**Mandate:** 3 Year Term & Renewal

**Members** can be from:

- Patient Organisations
- Hospital and Academic Institutions
- Research Groups and Networks
- Social Care Sector Organisation and Education & Employment Institutions
- National and Local Authorities & Policy Institutions
EURORDIS Mental Wellbeing Partnership Network

Call to join the Partnership Network ...

... for patient representatives, medical expertise and researchers.

Email: Concha Mayo on concha.mayo@eurordis.org
EURORDIS Mental Wellbeing Web Page

Mental Health & Wellbeing

There is no health without mental health. The relationship between physical and mental health is well established. Increased stress and complexity of a physical health condition, in turn increases the risk to mental health and well-being (result in higher rates of depression, anxiety and also where poor mental health can impact on physical health, the capacity to work, resilience). (King’s College London College of Physicians & Surgeons (Mental Health Foundation (4)).

Mental health is a basic human right. The World Health Organization’s definition of mental health (5) seeing it as something that is strongly linked to opportunities, and participation in the community:

A state of mental well-being that enables people to cope with the stresses of life, realize their abilities, learn well, (making healthy choices) and work well, and contribute to their community. It is an integral component of health and well-being that underpins our individual and collective abilities to make decisions, build relationships and shape the world we live in. And it is crucial to personal, community and socio-economic development.

Impact of Rare Disease on Mental Wellbeing

People living with a rare disease and their families face increased stress and risk factors, resulting in them experiencing an accumulative impact on their mental wellbeing, specifically at an individual level.

At an Individual Level
Mental health is an associated with morbidity and mortality for many rare diseases.

At a Population Level
Increased psychological impact associated with the rare disease journey across all stages of life.

Crisis-cutting psychosocial determinants
People living with a rare disease and their families have increased exposure to social inequalities and discrimination, which are risk factors and determinants of poor mental wellbeing.

EURORDIS Action to Improve the Mental Wellbeing of the Rare Disease Community

EURORDIS has to leverage the opportunity of the new Communication on a Comprehensive Approach to Mental Health to make visible the unmet mental health needs of people living with a rare disease and their families and take affirmative action to address these needs.

A new EURORDIS Mental Wellbeing Initiative is planned to be launched in 2020 to address the unmet mental health needs of people living with a rare disease and their families. The EURORDIS Mental Wellbeing Initiative is co-led by the Rare Disease Institute (RDI) and the Rare Disease Network (RDN).

EURORDIS will establish a new EURORDIS Mental Health Partnership Network (Partnership Network) to support and coordinate the development and delivery of various activities in the framework of EURORDIS Mental Wellbeing Initiative.

The Partnership Network will bring together experts and stakeholders to drive a community action on mental health and wellbeing for people living with a rare disease, their families and caregivers. Specifically, the Partnership Network will unite and empower the rare disease community to come together, learn, take action and tell recommendations to the specific needs of people living with a rare disease, in all policy areas, to ensure the mental health and wellbeing of the rare disease community is improved.

Applications for our new Partnership Network are still open. EURORDIS is looking for dedicated volunteers to be active in the Partnership Network.

If the rare disease you represent has an impact on the mental health and wellbeing, we would like to hear from you and ensure that your expertise and insights are included to shape the work of the Partnership Network.

https://www.eurordis.org/mental-wellbeing/

Register to join Partnership Network
EURORDIS Mental Wellbeing Initiative

Four-year initiative supported by a new EURORDIS Mental Wellbeing Partnership Network.
Overview of the Initiative

Pillar 1: Network & Community Engagement
- New EURORDIS MH Partnership Network
- Community Engagement
- Advocacy in All Policy Areas

Pillar 2: Evidence Generation
- Literature Review on Unmet Needs
- Population Survey
- Targeted Literature on Solutions

Pillar 3: Best Practice & Capacity Building
- Peer Learning Programme
- Mentally Healthy Communities Toolkit
- Care Standards & Pathways

Pillar 4: Awareness & Communication
- Public Awareness Campaign
- Communication Strategy
- Communication Activities & Tools

Pillar 5: Management & Stakeholder Engagement
- Management, Monitoring & Impact
- Engagement Strategy
- Funding Opportunities
Thank you!

Please complete the webinar survey