

# *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

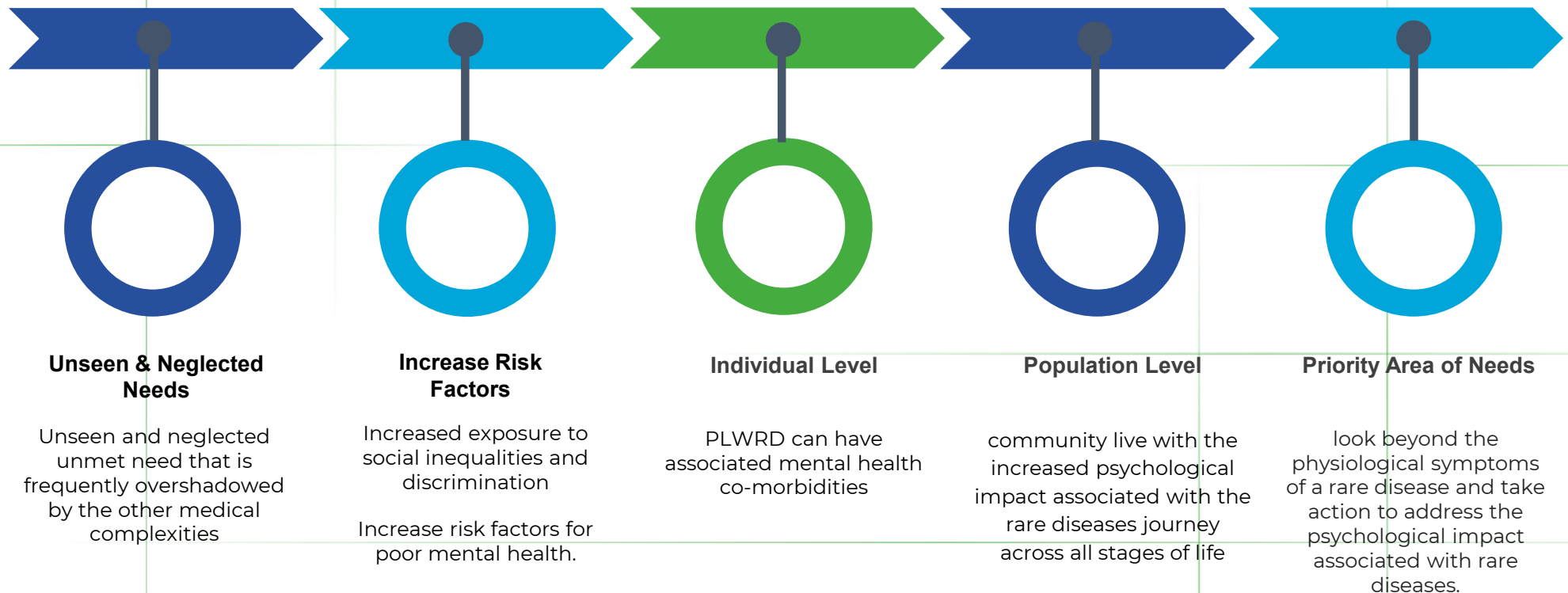
**Webinar will be recorded**



# Welcome & Opening Remarks



# Accumulative Impact on Wellbeing



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

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**Policy and  
Knowledge Officer**

**Mental Health  
Europe**



Kym Winter

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**Founder & Clinical  
Director**

**Rare Minds**



Avril Daly

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**Retina International**

**President OF  
EURORDIS**



Tom Kenny

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**Chief Executive  
Officer**

**Rare Disease  
Research Partners**



Matt Bolz-Johnson

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**Mental Wellbeing  
Lead**

**EURORDIS**

# Agenda

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

# Defining Mental Health & Europe - Response to addressing the Public Health Priority

Fatima Awil, Mental Health Europe

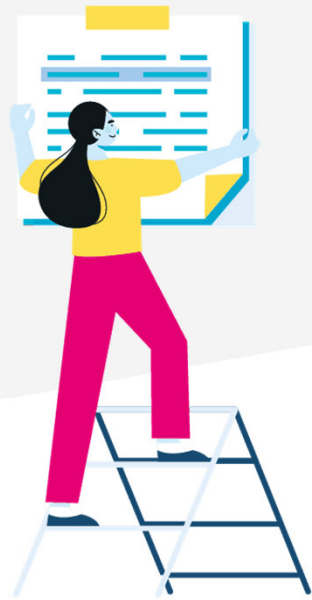




The World Health Organisation (WHO) defines mental health as “a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.”



- 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



Expected & unexpected life circumstances

Poverty

Positive norms

Lack of social support

Opportunities to pursue interests

Social relationships

Risk Factors

Protective Factors

Early childhood lack of care

Substance abuse

Good support system

Physical and psychological safety

Bullying

Traumatic Event

Physical health

# United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)



- UN CRPD is 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



- Green Paper on “Improving the mental health of the population - towards a strategy on mental health for the European Union” (2004)
- 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

<b>Service Provision</b>	<b>Training &amp; Support</b>	<b>Research &amp; Awareness</b>
<p>Couples/individual counselling.</p> <p>Group programmes.</p> <p>Workshops.</p> <p>Self-help psycho-educational resources.</p>	<p>Clinical supervision for front-line workers.</p> <p>Rare leader training, group supervision &amp; consultancy.</p> <p>Workshops, training &amp; courses for HCP.</p> <p>Partnership working.</p>	<p>Presenting at conferences, stakeholder, partners &amp; industry events.</p> <p>Contributing case studies &amp; expert opinion.</p> <p>Build data - initiating &amp; contributing to research.</p> <p>Inform policy and practice</p>

# 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, treatments, 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

# Impact on Mental Health



## Rare Disease UK Report (2018)

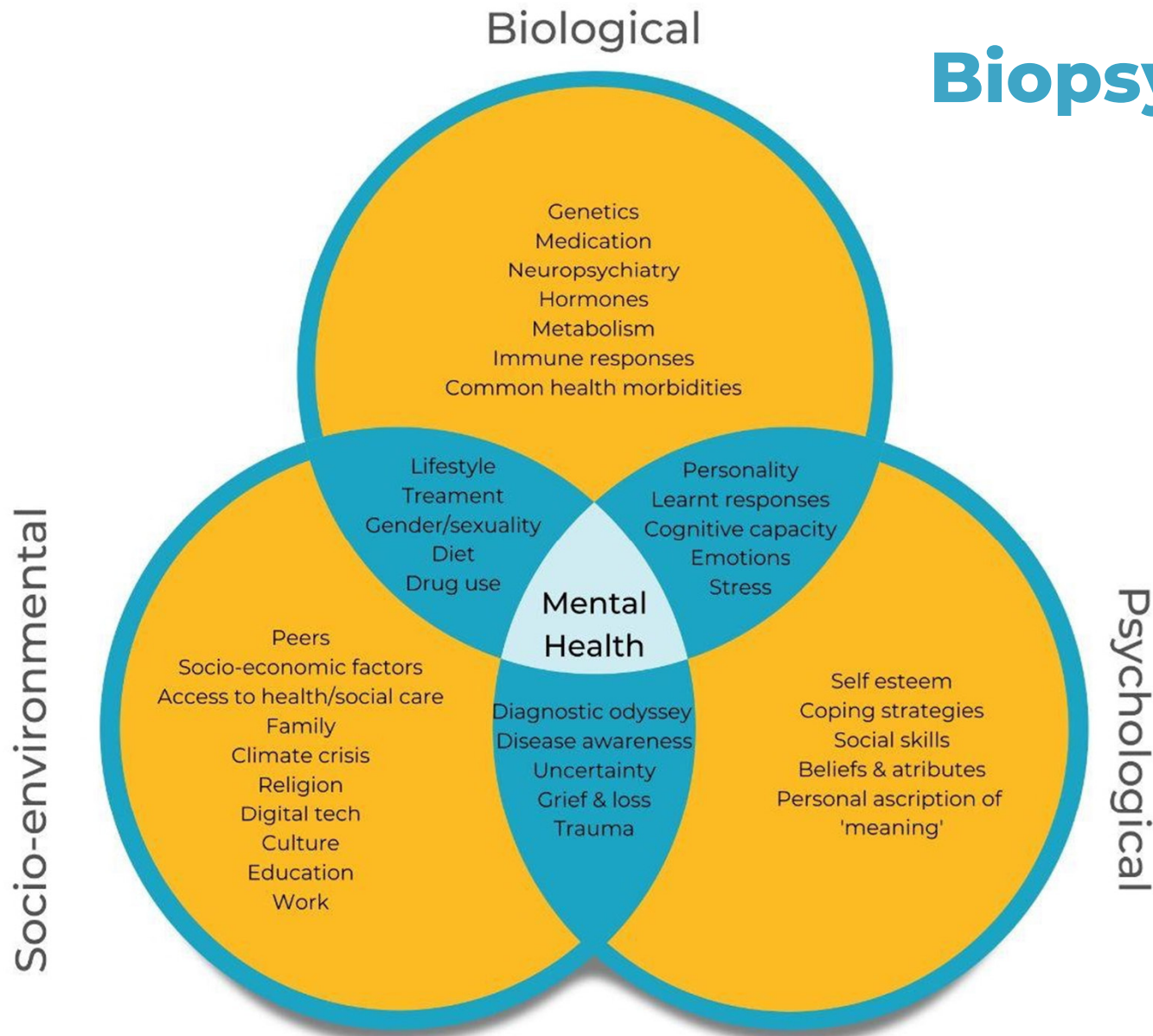
95% have felt worried or anxious  
93% have felt stressed  
90% have felt low  
88% have felt emotionally exhausted  
70% have felt at breaking point  
36% patients / 19% carers experienced suicidal thoughts

**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



# 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](http://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 PAGES ( 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'

#RareDiseaseDay #CareForRare #MentalHealth #RareMindsMatter

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



Rare Minds Matter: Mental Health Survey 2023  
[www.bit.ly/rarementalhealthsurvey](http://www.bit.ly/rarementalhealthsurvey)

**Survey:** If based in the UK, please complete our survey:  
[www.bit.ly/rarementalhealthsurvey](http://www.bit.ly/rarementalhealthsurvey)

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).

rareminds  
Mental Health for the Rare Disease Community

[www.rareminds.org](http://www.rareminds.org)

**Thank you**

rareminds  
Mental Health for the Rare Disease Community





Rare Disease  
Research Partners

Iris, Ehlers-Danlos syndrome, chronic paroxysmal hemicrania, cluster headaches

# 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

Hand searched references  
n = 550

Total papers  
found  
n = 1274

SCREENING

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

RESULTS

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

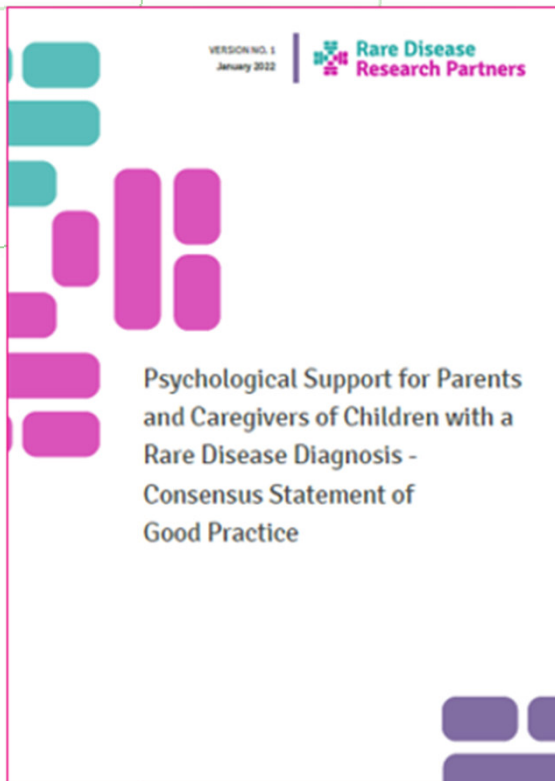
Developing support systems

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

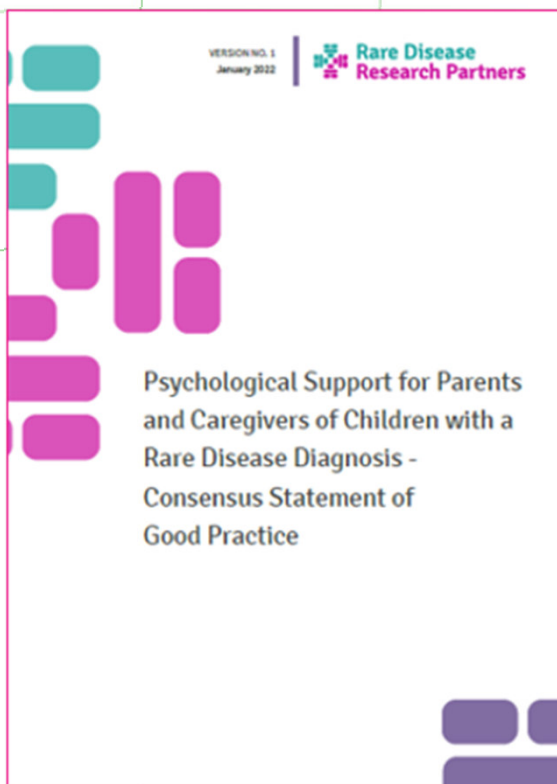
Single Co-ordinating Professional

# Statement of Good Practice

## 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*

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

# Curated Information

*A reliable source of curated information*

<i>Recommendations</i>	<i>Grading</i>
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	Strong
2. Signposting for parents and caregivers to relevant and accessible financial and mental health support services	Weak

# Access to Expertise

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## *Access to expertise*

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### *Recommendations*

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### *Grading*

- 
1. 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
- 

Strong

# Access to a Psychological Practitioner

*Access to a psychosocial healthcare practitioner*

*Recommendations*

*Grading*

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

Strong



# Single Co-ordinating Professional

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

*Recommendations*

1. 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	Moderate
2. Experts need to actively share disease knowledge with the co-ordinating professional	Strong

**Thank you**



Serving rare disease communities

# Q&A and Panel Discussion





Kacper from Poland is living with Kawasaki disease

# EURORDIS Advocacy Action



# Mental Wellbeing Workshop, EMM2023

## 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



## EURORDIS Mental Wellbeing Partnership Network

### Network Terms of Reference

Adopted on the 06 July 2023

#### Introduction

People living with a rare and undiagnosed condition experience an accumulative impact on their mental wellbeing. At an individual level, people living with a rare disease (PLWRD) can have an associated mental health co-morbidity, whereas at a population level, the community lives with the increased psychological impact associated with the rare diseases journey across all stages of life. In addition, PLWRD and their families have increased exposure to social inequalities and discrimination, which are risk factors and determinants for poor mental wellbeing.

EURORDIS has established a Mental Health Partnership Network in order to take action to the rare disease community call to look beyond the physiological symptoms of a rare condition, with a specific focus on fostering increased access to psychological support as a fully integrated part of the coordination of care and ensuring it is routinely available at diagnosis and throughout the following care pathway.

#### Purpose

The EURORDIS Mental Health Partnership Network (Partnership Network) will bring together experts and stakeholders to drive a community action on mental health and wellbeing for PLWRD, their families and caregivers.

Specifically, the Partnership Network will unite and empower the rare disease community to come together, learn, take action and tailor recommendations to the specific needs of PLWRD in all policy areas, to ensure that the mental health and wellbeing of the rare disease community is improved. The findings of the Network will feed into EURORDIS' work across all policy areas, specifically through:

- increased access to quality preventative measures, early detection and treatment services, improving health promotion, and ensuring more people recover.
- tackle inequalities, stigma and discrimination among the rare disease community experiencing poor mental health and wellbeing.
- taking action to contribute to addressing the underpinning socio-economic and environmental determinants on mental health in the rare disease community.

#### Mission

Through collaboration of experts – medical, research and by lived experience, the Partnership Network will 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.

1

**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](mailto:concha.mayo@eurordis.org)



# EURORDIS Mental Wellbeing Web Page

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

# 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



# Closing Remarks





Iris, Ehlers-Danlos syndrome, chronic paroxysmal hemicrania, cluster headaches

# Thank you!

# Please complete the webinar survey

