

Mental Wellbeing Update

CNA & CEF Meeting, 08.02.2023



Overview of EURORDIS' Advocacy Activity in 2023

Q1, 2023

- MEP Key Ask on Mental Health, RDW
- Gathering Evidence
- Submitted Response for the Call for Evidence on RD & MH
- Attended EP Policy Event
- Submitted a Poster of a Concrete Action
- Developed EURORDIS Mental Wellbeing Initiative
- Joined the EC MH Advocacy Platform



Q3, 2023

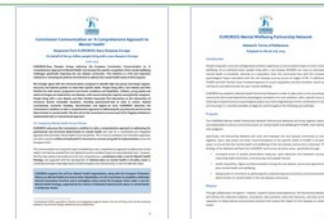
- New Webpage on Mental Wellbeing
- Launched a call to join new Partnership Network
- 1st Webinar on Impact of RD on Mental Wellbeing
- 2nd Webinar on Living with Uncertainty & Dealing with Trauma
- ERTC Webinar on Mental Wellbeing
- Contribution to MEP Own Initiative (INI) Report
- RBV Factsheet on Mental Health & Wellbeing



- Rare on Air Podcast & Blog
- EMM Satellite Workshop on Mental Wellbeing, Stockholm
- Approval of Terms of Reference for EURORDIS Partnership Network EURORDIS became a member of Mental Health Europe (MHE) and develop strategic partnerships with GAMIAN Europe and MHE
- EC publish new Communication Mental Health
- Published a Media Statement & submitted Full Response on the new Communication

- World Mental Health Day
- Launch new EURORDIS Partnership Network
- Mental Health Session at WODC
- EP Policy Event on People in Vulnerable Situations
- Draft Outline Position Paper

Q2, 2023



Q4, 2023



ΜΕΨΗΗ, ρΡ ΔΨΕΨΟ Ι ΡΦΜΦΙ ΡΦ

Addressing the Risks and Barriers Faced by People in Vulnerable Situations, Brussels, 28.11.2023



MEP co-host: MEP Tilly Metz, Green Party & MEP Sara Cerdas, Socialist Party

Objectives:

- To set out what we mean by the “psychosocial model of mental health” highlighting the intersectional needs of people in vulnerable situations.
- To look into the future and explore what we want to see developed as part of the implementation of the new Communication and identify EU action that can best address the social determinants and intersectionality.

Outcome:


A call to secure continued political commitment to address mental health as a priority under the new European Parliament:

- For the continued prioritisation of mental health, beyond the new Communication.
- For future European actions in Mental Health to be inclusive of all people in vulnerable situations, leaving no one behind.



Own Initiative Report

European Parliament
2019-2024



Subcommittee on Public Health

2023/2074(INI)

28.7.2023

DRAFT REPORT

on mental health
(2023/2074(INI))

Subcommittee on Public Health

Rapporteur: Sara Cerdas

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PE751.899v03-00

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United in diversity



EUROPEAN PARLIAMENT

Committee on the Environment, Public Health and Food Safety

07/09/2023

Sara Cerdas
Mental health

Motion for a resolution PE751.899 - 2023/2074(INI)

Amendment 33
Susana Solís Pérez, Catherine Amalric, Frédérique Ries

Motion for a resolution
Paragraph 2 b (new)

Motion for a resolution

Amendment

2 b. Underlines the heightened vulnerability to mental health problems in specific groups, namely: children and youth, the elderly, those experiencing dual disorders, people with physical or mental disabilities, individuals experiencing significant loneliness due to insufficient social connections, people living with HIV, displaced individuals including refugees and migrants, LGBTI people, victims of violence, incarcerated individuals, individuals with chronic conditions, rare diseases and those residing in rural or isolated areas. Their increased vulnerability is due to unique challenges faced by each group, which can exacerbate mental health issues;

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- Underlines the heightened vulnerability to mental health problems in specific groups, namely: **children and youth, the elderly, those experiencing dual disorders, people with physical or mental disabilities, (..), individuals with chronic conditions, rare diseases** and those residing in rural or isolated areas. Their increased vulnerability is due to unique challenges faced by each group, which can exacerbate mental health issues.
- Calls on the Member States to improve access to care, treatment and support for mental health conditions by implementing holistic multidisciplinary care and enhancing integrated pathways between services for **people with mental health disorders and other comorbidities** while taking account of social, psychological as well as biological factors, patient centredness and patient choice.
- **Toolkit for people in a vulnerable situations.**

ΕΛΛΗΝΙΚΗ ΔΗΜΟΚΡΑΤΙΑ ΥΠΟΥΡΓΕΙΟ ΥΓΕΙΑΣ ΚΑΙ ΚΟΙΝΩΝΙΑΣ ΚΑΙ ΑΝΤΙΣΤΡΑΤΕΓΙΚΗΣ ΠΡΟΒΛΕΨΗΣ



Outline Position Paper on Mental Health & Wellbeing EURORDIS-Rare Diseases Europe

On behalf of the 30 million people living with a rare condition in Europe

07 November 2023

Executive Summary

Rare conditions impact the mental health and wellbeing of not only the affected individual but their support network (family and friends). The population of people living with a rare disease (PLWRD) in the EU are in a vulnerable situation due to the accumulated impact of multiple intersectional needs and require tailored actions in all policy areas to address these needs. The majority of rare conditions appear in childhood and the mental health burden on these children is very high as well as on their siblings and parents.

It is not surprising that rare conditions have an associated impact on mental health, as the connection between physical and mental health is well established. Increased severity and complexity of a physical health condition in turn increases the risk to mental health and wellbeing. (King's Fund, 2012; Royal College of Psychiatrists and Centre for MH, 2013). While this is true for both chronic conditions and rare conditions, the latter present additional problems that are specific to their low prevalence, highlighting the increased psychosocial vulnerability of PLWRD. Published evidence demonstrates that depression and anxiety coupled with chronic conditions and rare conditions are associated with reduced quality of life and can negatively affect the course of the illness. (Katon et al, 2007; Lichtman et al, 2014).

The impact of rare conditions on the mental health and wellbeing of the rare disease community has been widely recognised in global public health policy. The United Nations General Assembly (UNGA) acknowledged the accumulated intersectional needs of PLWRD and their families in the UNGA Resolution "on Addressing the Challenges of Persons Living with a Rare Disease and their Families" (RES/76/132, 2021), and specifically "urges Member States to implement effective programmes to promote mental health and psychosocial support for persons living with a rare condition, and to promote policies and programmes that enhance the well-being of their families and caregivers".

Following the recent COVID-19 pandemic, the World Health Organization and the European Commission have identified mental health as a global public health priority, with a call for action to address this global crisis. It is therefore timely to take action to implement the UNGA call to develop psychosocial programmes for PLWRD and their families.



UN General Assembly Resolution on Addressing the challenges of persons living with a rare disease and their families:

- 10. Urges Member States to implement effective programmes to promote mental health and psychosocial support for persons living with a rare disease, and to promote policies and programmes that enhance the well-being of their families and caregivers. [A/RES/76/132](#)

World Health Organisation, 2022:

The World Health Organization (WHO) recognized “people with an existing health condition” as one of the main vulnerable groups who were more likely to develop symptoms of mental disorders following the pandemic, along with young people and women ([WHO 2022](#)).



Μελέτη της ΑΡΨΕ

- Η ΑΡΨΕ είναι η πιο κοινή ψυχιατρική παθολογία που αφορά άτομα με σπάνια νοσήματα. Η μελέτη αυτή διεξήχθη στην Ελλάδα και στο Ηνωμένο Βασίλειο, με σκοπό να διερευνηθεί η επίδραση της ΑΡΨΕ στην ποιότητα ζωής των ασθενών και των οικογενειών τους. Τα αποτελέσματα της μελέτης δημοσιεύθηκαν στο περιοδικό [Journal of Clinical Pharmacy and Therapeutics](#).
- Η μελέτη αυτή αποτελεί μέρος της έρευνας που διεξάγει η ΑΡΨΕ για να κατανοήσει καλύτερα την επίδραση της νόσου στην ψυχική υγεία των ασθενών. Τα αποτελέσματα της μελέτης θα χρησιμοποιηθούν για να βελτιωθούν οι παρεχόμενες υπηρεσίες ψυχιατρικής φροντίδας.

Common Needs in Uncommon Conditions¹

UN GA Resolution A/RES/76/132 (2021)



מבין הצרכים הנפוצים ביותר של אנשים עם מחלות נדירות, צורך מרכזי הוא בתמיכה פסיכוסוציאלית. צורך זה כולל: ייעוץ, תמיכה רגשית, מידע ותמיכה מעמיתת. צורך זה נובע מן העובדה שרוב אנשים עם מחלות נדירות אינם מקבלים תמיכה פסיכוסוציאלית מספקת במסגרת מערכת הבריאות.



National: visibility of mental health in rare disease national plans and strategies specifically to establish psychosocial support programmes through “psychologically informed medical care .

1. UN GA Resolution A/RES/76/132 (2021)
 “The Secretary-General is urged to continue to work with Member States to ensure that the needs of persons with rare diseases are taken into account in the development of national policies and strategies, and to continue to work with Member States to ensure that the needs of persons with rare diseases are taken into account in the development of national policies and strategies, and to continue to work with Member States to ensure that the needs of persons with rare diseases are taken into account in the development of national policies and strategies.”

What does psychosocial care look like to you?

Practice Support
Social Support
Coping with
Uncertainty
Need for
Information
Integrated
approach
Interdisciplinary
Care
Strengthen
recourses and
resilience
Empathic
Communication
Psychological
Support
Family-
focused Care

Mental Wellbeing Communication

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

Home \ Mental Health & Wellbeing

Mental Health & Wellbeing

There is no health without mental health. The relationship between physical and mental health is well established. Increased severity 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 self-care, resilience. (King's Fund¹, Royal College of Psychiatrists & Centre for Mental Health², Mental Health Foundation³).

Mental health is a basic human right. The World Health Organization's definition of mental health⁴, 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 choice) 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 and undiagnosed condition have increased vulnerability 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 co-morbidity for many rare diseases.

At a Population Level

Increased psychological impact associated with the rare diseases journey across all stages of life.

Cross-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 for poor mental wellbeing.

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

EURORDIS wishes 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.

Pillar 1
Network & Community Engagement

- New Eurordis Mx 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
- Sharing Best Practice Platform
- Mental Health Communities Toolkits
- 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

A new EURORDIS Mental Wellbeing Initiative is planned to be launched in 2023-24, with the overarching objective to **promote the development of a 'mentally healthy community'** that reduces the accumulated impact of rare diseases on mental health and wellbeing among people living with a rare disease and their families.

EURORDIS new Mental Wellbeing Partnership Network

EURORDIS will establish a new EURORDIS Mental Health Partnership Network (Partnership Network) to support and coordination of the development and delivery of community 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 tailor 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. The findings of this network will feed into EURORDIS work across all policy areas.

EURORDIS launched a call for expressions of interest to join the new Partnership Network at a EURORDIS Membership Meeting (EMM 2023) Satellite Working – Enhancing the Mental Wellbeing in the Rare Disease Community held on the 25.05.2023.

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.

[Apply here](#)

Podcast Episode
Mental wellbeing with a rare disease
Rare on Air

Valuing Mental Wellbeing in the Rare Disease Community

May 2023

The recent COVID-19 pandemic was a wake-up call to the importance of the physical health of citizens to both society and the economy. In recent months, the importance of the mental health of citizens, and the population as a whole, has only just started coming to light and being recognised by policy makers, politicians and governments.

Even in the rare disease community, physical health has long been prioritised over mental health. The quest to secure a diagnosis, access to treatments, and drive research to find a cure have all overshadowed the psychological impact endured by those who have travelled along the rare disease journey.

x3

People living with a rare disease and their families are three times more likely to report being unhappy and depressed compared with the general population.

EURORDIS' Rare Biomarker Juggling Life and Care Survey

When engaging with ePAG Advocates active in the European Reference Networks to map the needs that are specific to their rare disease, one common theme quickly surfaced: the accumulated and detrimental impact on mental health and wellbeing. When faced with living with an undiagnosed or rare disease, it seems we only have two options; either we are in crisis management mode or we are alone.

What is 'mental wellbeing'?

To be able to have this critical and long-overdue conversation about our mental health, we first need to find a common definition of what mental health actually is. Many people use the term to indicate a negative state of being, as opposed to seeing mental health as an integral component of our broader health and wellbeing, which enables us to realise our full potential and participate in society. There is no health without mental health!

Mental health is dynamic and fluid, forever changing, and best seen on a continuum. You can move across the continuum from being in good health to being in distress or dealing with challenges and problems and back again. It can impact our mood, behaviour and cognition, expressed through our stresses, anxiety, perceptions and obsession. When it is persistent and pervasive it can be associated with significant distress and impacts on functioning and daily living. There are many factors that affect mental health and wellbeing, for example brain injury, infection, fever, hormone or neurological problems. Additionally, economic factors can impact your wellbeing, such as cost-of-living-crisis, inability to work and live independently, or social and environmental factors like social media, experiencing prejudice

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The Impact of Rare Diseases on Mental Wellbeing Webinar
June 2023

13 July 2023 at 15.00-16.30 CET

Factsheet 1: Defining the Psychosocial Determinants that affect our Mental Health & Wellbeing

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Living with Uncertainty & Impact of Trauma Mental Wellbeing Webinar
August 2023

Factsheet 3: RBV Juggling Care & Life – Mental Health & Wellbeing

Factsheet 4: The accumulated impact of living with multiple intersectional needs.

3rd Webinar

The Diagnostic Odyssey's Impact on Mental Health Webinar
20 March 2024 at 11.00-12.30 CET

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Factsheet 6: Protection factors to addressing with uncertainty

EURORDIS Mental Health & Wellbeing Factsheet(s)

THE SOCIAL IMPACT OF RARE DISEASES ON MENTAL HEALTH & WELL-BEING

August 2016 - February 2017 | 3,071 respondents in Europe | 806 diseases represented | 42 countries

People living with a rare and undiagnosed condition have increased vulnerability and risk factors resulting in them experiencing an accumulative impact on their mental wellbeing, specifically at an individual level.

3 times more people living with a rare disease reported being unhappy and depressed than the general population.*

47% people living with a rare disease said that their needs for psychological support were not met.

54% people living with a rare disease declare that the rare disease caused or amplified isolation from friends and family.

7/10 reduced or stopped professional activity due to their own or their family members' disease.

HEAR IT FROM THE RESPONDENTS THEMSELVES

"SIMPLY GETTING A DIAGNOSIS WAS A FIGHT. THE DISEASE HAS A HUGE IMPACT ON OUR MOBILITY, OUR PHYSICAL HEALTH AND OUR MENTAL HEALTH."
PATIENT'S PARENT OF CHILD WITH RARE DISEASE, UK

"OUR CHILD'S ILLNESS GIVES NO RESPIRE. WE FEEL A TOTAL LOSS OF CAREFREEDOM, CONSTANT APPREHENSION OF THE FUTURE AND ANXIETY. WE HAVE VERY LITTLE PSYCHOLOGICAL SUPPORT AND IT FEELS LIKE THE ILLNESS IS SEPARATING US FROM OUR LOVED ONES. THEY DO NOT REALIZE THE EXTENT OF OUR DAILY DIFFICULTIES."
PARENT OF CHILD WITH RARE DISEASE, FRANCE

* Rare Barometer sample compared to International Survey Programme, 2011.

30 million people are living with a rare disease in Europe and 300 million worldwide | No cure for the vast majority of diseases and few treatments available | Thank you to everyone who participated in the survey, and to the Rare Barometer partner!

For more information visit eurordis.org/rare-barometer or email rare.barometer@eurordis.org

Factsheet #1: Defining the Psychosocial Determinants that affect our Mental Health & Wellbeing

Mental health is a fundamental part of being human. It is expressed in our mood, emotions, thoughts, cognition, control and behaviours. Our mental health is in a constant state of flux, influenced by a range of psychosocial and environmental factors as well as health determinants.

WHO Definition:
Mental health is a state of mental well-being that enables people to cope with the stresses of life, realize their abilities, learn well 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. Mental health is a basic human right.

Mental health is not the presence or absence of mental disorders. It exists on a complex continuum, which is experienced differently from one person to the next, with varying degrees of wellbeing, difficulty and distress, and potentially very different social and clinical outcomes.

Mental health issues include mental disorders and psychosocial disabilities as well as other mental states associated with significant distress and impairment in functioning. People with mental health conditions are more likely to experience lower levels of mental well-being, but this is not always or necessarily the case.

Psychosocial Determinants:
Health, both physical and mental health, can be influenced and affected by different factors, known as 'determinants of health', including economic and social status, education, physical environment, social support networks, gender, genetics and access to and use of health services. These 'psychosocial' factors are both protective in nature and can also pose a risk to poorer health.

Example of psychosocial factors:

Protection Factors	Risk Factors
<ul style="list-style-type: none"> Positive norms Opportunities to pursue interests Social relationships, community and networks Good physical health Physical and psychological safety Good support system 	<ul style="list-style-type: none"> Poverty, cost of living and ability to work Bullying and experiencing prejudice Lack of supportive relationships, family breakdown, domestic abuse Injury, infections and health issues Substance abuse Lack of social support Forced displacement and humanitarian emergencies

Factsheet #2: Impact of Rare Conditions on Mental Health & Wellbeing

There is no health without mental health. Poor physical health can increase the rate of depression and anxiety. Poor mental health can impact on physical health, the capacity to self-care and reduce resilience.

The accumulated impact of rare conditions on mental health and wellbeing can occur at both an individual and population level. 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 disease journey across all stages of life.

The rare disease community have called for us to now look beyond the physiological symptoms and take action to address the psychological impact that is associated with rare conditions (EURORDIS Rare2030 Recommendations, 2020). The community have reported that their psychological and emotional needs are not routinely taken into account in their care and treatment.

Impact of the Rare Disease Journey:
The rare disease journey has unique stressors that directly impact on the mental health and wellbeing of all people who travel this journey. Specifically, the diagnostic odyssey is often lengthy and traumatic, paved with a history of misdiagnosis and poor communication of diagnosis. How a rare disease diagnosis is given can cast a long shadow across the whole of the future rare disease pathway. When done badly it can reduce trust in all healthcare professionals; but when it is done well, it can empower the affected individual and family to best cope with an uncertain future and unpredictable life.

Living in uncertainty is a common reality for the majority of the rare disease community. Uncertainty is strongly associated with anxiety. The low awareness of rare conditions among professionals / public, can also increase feelings of isolation and frustration.

The high logistical burden of living with a rare condition, and care management, can increase the emotional impact on families who may have problems accessing treatment and supports and may have to endure frequent monitoring, agonising waits for test results and invasive treatments. This can increase the traumatic experience of healthcare, especially for children and young people.

The combined effect of these strains and stressors impact on family life as a whole and on parental and family relationships. For genetic conditions, there can also be an impact of genetic inheritance on identity, and life choices. This can also cause grief of a future and life loss, and unwarranted guilt from passing on a genetic condition.

Factsheet #3: The accumulated impact of living with multiple intersectional needs.

People living with a rare disease and their families live with severe, progressive and chronic conditions and disabilities. Children, young adults and adults of all ages are impacted by rare diseases, with women being the majority among family caregivers. People living with a rare disease and their families frequently find themselves at the intersection of numerous diverse vulnerable situations, including psychosocial risks at work or school, medical uncertainties, economic hardship, discrimination and stigma.

EURORDIS Rare Barometer Voices Survey on the impact of the COVID-19 pandemic, 2020, showed that:

- 2/3 of respondents suffered from depression and/or a feeling of not being able to overcome their problems since the beginning of the pandemic.
- 6 in 10 found the interruptions to care detrimental to their health or the health of the person they care for. 3 in 10 perceive that these interruptions to care could even probably (21%) or definitely (9%) be life-threatening.

Quote: "The first weeks of COVID I had fears. Suddenly there was no longer much help or contact. Some operations that should have been done have been postponed. I'm really waiting for that. I'm in a lot of pain right now. In addition, I have the feeling that I am on my own." Person living with a rare disease.

People in vulnerable situations

The World Health Organization (WHO) confirmed EURORDIS RBV survey results and also recognized "people with an existing health condition" as one of the main vulnerable groups who were more likely to develop symptoms of mental disorders following the pandemic, along with young people and women (WHO 2022).

The European Commission also highlights the following groups to have higher level of risks to good mental health.

- Children & Young People
- Older People
- Cancer patients and survivors
- People living with disabilities
- Chronic conditions & multi-comorbidities
- Migrant and refugee populations
- Ethnic minorities
- People from lower socio-economic backgrounds
- LGBTIQ+ people
- Women
- Victims of gender-based violence
- Victims of trafficking in human beings
- Victims of crimes
- Roma
- People living in rural or remote areas

Factsheet 1: RBV Juggling Care & Life – Mental Health & Wellbeing

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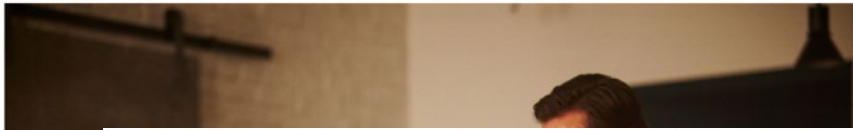
Factsheet 3: Impact of Rare Conditions on Mental Health & Wellbeing

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IN MEMORIAM



EUROPEAN
MENTAL
HEALTH
WEEK | 22-28
MAY 2023

mieli
Mental Health Finland

Well-being at
the workplace

Measuring how living with a rare disease impacts our mental health: Case study of the resilience of people living with Neurofibromatosis Type 1

Claas Röhl, President of NF Kinder.



As a father living in Austria, my life took an unexpected turn when my daughter was just three months old, and the first signs of a rare condition called Neurofibromatosis Type 1 (NF1) surfaced. NF1 is a genetic condition that causes tumours to grow in the nervous system. The first symptoms commonly are café-au-lait spots, which are dark pigmented patches on the skin. The following months were a whirlwind of uncertainty, doctor appointments and tests, searching for a specialist who could tell us what these spots were, resulting in mounting concerns and anxiety before we finally received the diagnosis. Looking back, this period of ambiguity and searching for answers was one of the darkest and most challenging times for my wife and I as parents, as we were still hoping that there may be another explanation for these spots, and they would not connect to NF1. We were still hoping there would be an end to this nightmare and receive good news.

Receiving the diagnosis extinguished the last glimmer of hope and was a traumatic event for the whole family. However, it also helped us to focus our energy on learning about NF1 and understanding what we could do as parents. As a result, we learnt that NF1 is a genetic condition without a cure, that it will not go away, and it will accompany our family throughout our whole life. The condition affects all body systems and has a poor prognosis. It is highly unpredictable, with more than 100 potential symptoms and health threats throughout life, including different types of cancers. This was a tough pill to swallow, as being faced with all the different possibilities was overwhelming. Our internet searches gave a distorted picture of NF1, presenting us with images of the most extreme cases. It was frightening to us to view so many pictures of severe manifestations of the condition, such as pictures of people being covered with thousands of skin tumours or exhibiting large facial tumours or orthopaedic complications.

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Measuring how living with a rare disease impacts our mental health: Case study of the resilience of people living with Neurofibromatosis Type 2
 Chae RHM, President of NF Kinship

As a father living in Austria, my life took an unexpected turn when my daughter was just three months old, and the first signs of a rare condition called Neurofibromatosis Type 2 (NF2) surfaced. NF2 is a genetic condition that causes tumours to grow in the nervous system. The first symptoms commonly are café-au-lait spots, which are dark pigmented patches on the skin. The following months were a whirlwind of uncertainty, doctor appointments and tests, searching for a specialist who could tell us what these spots were, resulting in mounting concerns and anxiety before we finally received the diagnosis. Looking back, this period of ambiguity and searching for answers was one of the darkest and most challenging times for my wife and I as parents, as we were still hoping that there may be another explanation for these spots, and they would not connect to NF2. We were still hoping there would be an end to this nightmare and receive good news.

Receiving the diagnosis entrenches the last glimmer of hope and was a traumatic event for the whole family. However, it also helped us to focus our energy on learning about NF2 and understanding what we could do as parents. As a result, we learnt that NF2 is a genetic condition without a cure, that it will not go away and it will accompany our family throughout our whole life. The condition affects all body systems and has a poor prognosis. It is highly unpredictable, with more than 100 potential symptoms and health threats throughout life, including different types of cancers. This was a tough pill to swallow, as being faced with all the different possibilities was overwhelming. Our internet searches gave a distorted picture of NF2, presenting us with images of the most extreme cases. It was frightening to us to view so many pictures of severe manifestations of the condition, such as pictures of people being covered with thousands of skin tumours or exhibiting larger facial tumours or orthopaedic complications.



Message concha.mayo@eurordis.org



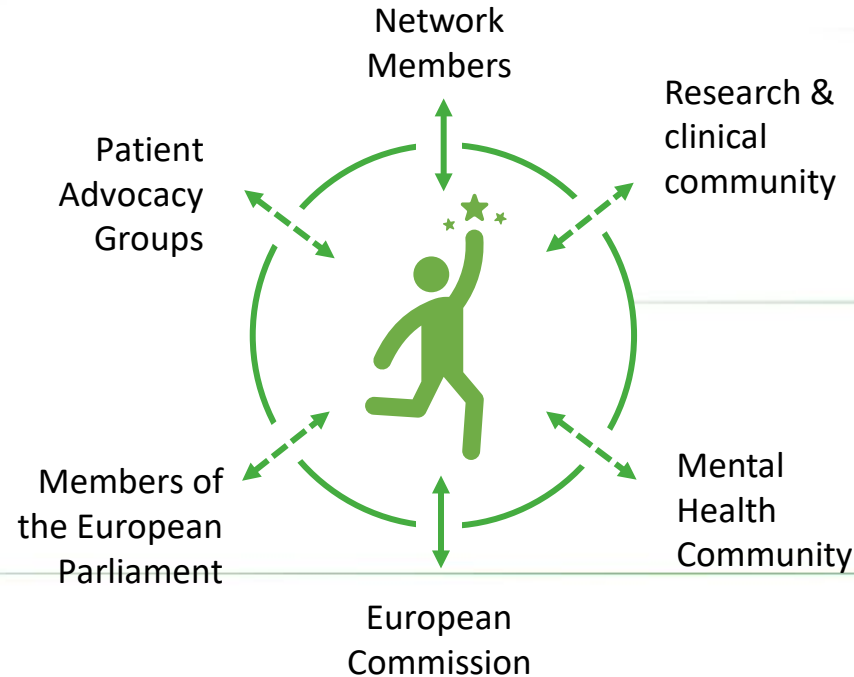
ΨΥΧΙΚΗ ΥΓΕΙΑ ΚΑΙ ΠΛΗΡΑ ΧΡΟΝΙΑ ΣΥΝΔΡΟΜΑΤΑ

Η ψυχική υγεία των ατόμων με ΠΛΧΣ είναι ζωτικής σημασίας για την ποιότητα ζωής τους. Η ψυχική υγεία των ατόμων με ΠΛΧΣ είναι ζωτικής σημασίας για την ποιότητα ζωής τους. Η ψυχική υγεία των ατόμων με ΠΛΧΣ είναι ζωτικής σημασίας για την ποιότητα ζωής τους.

Objectives

- Visibility and recognition of the mental health challenges faced by PLWRD.
- Promote greater awareness and inclusion of mental health in rare disease policies.
- Promote best and promising practices to strengthen capacities of the rare disease community to address the impact of rare conditions on mental wellbeing.

Target Stakeholders



Αποτελέσματα

- Είσοδος στην Ευρωπαϊκή Επιτροπή και στο Ευρωπαϊκό Κοινοβούλιο για την ψυχική υγεία των ατόμων με ΠΛΧΣ.
- Ήδη υλοποιηθείσα δράση για την ψυχική υγεία των ατόμων με ΠΛΧΣ.
- Δράση για την ψυχική υγεία των ατόμων με ΠΛΧΣ.
- Δράση για την ψυχική υγεία των ατόμων με ΠΛΧΣ.

Call

for
Best Practice



EURORDIS is opening a **call for best and promising practices** that have effectively addressed the mental health of a rare disease community ...

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EURODIS Mental Wellbeing Initiative

ὁ ἰσχυρὸς ΜΑ...ἔ...Εὐ... ἢ ἰσοφύλακτος ὁ ἰσοφύλακτος ἰσοφύλακτος ἰσοφύλακτος Δ...ἰσοφύλακτος ἰσοφύλακτος ἰσοφύλακτος

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Membership

Total No. of Network Members: >110

ERN ReConnect, ERN GENTURIS, ERN eUROGEN, ERN ERNICA, ERN EYE, ENDOERN, ERN BOND, ERN EPICARE, ERN ITHACA & ERN Rare Liver

18 EU Member States incl. Austria, Belgium, Bulgaria, Croatia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Malta, Netherlands, Portugal, Romania, Spain and Sweden

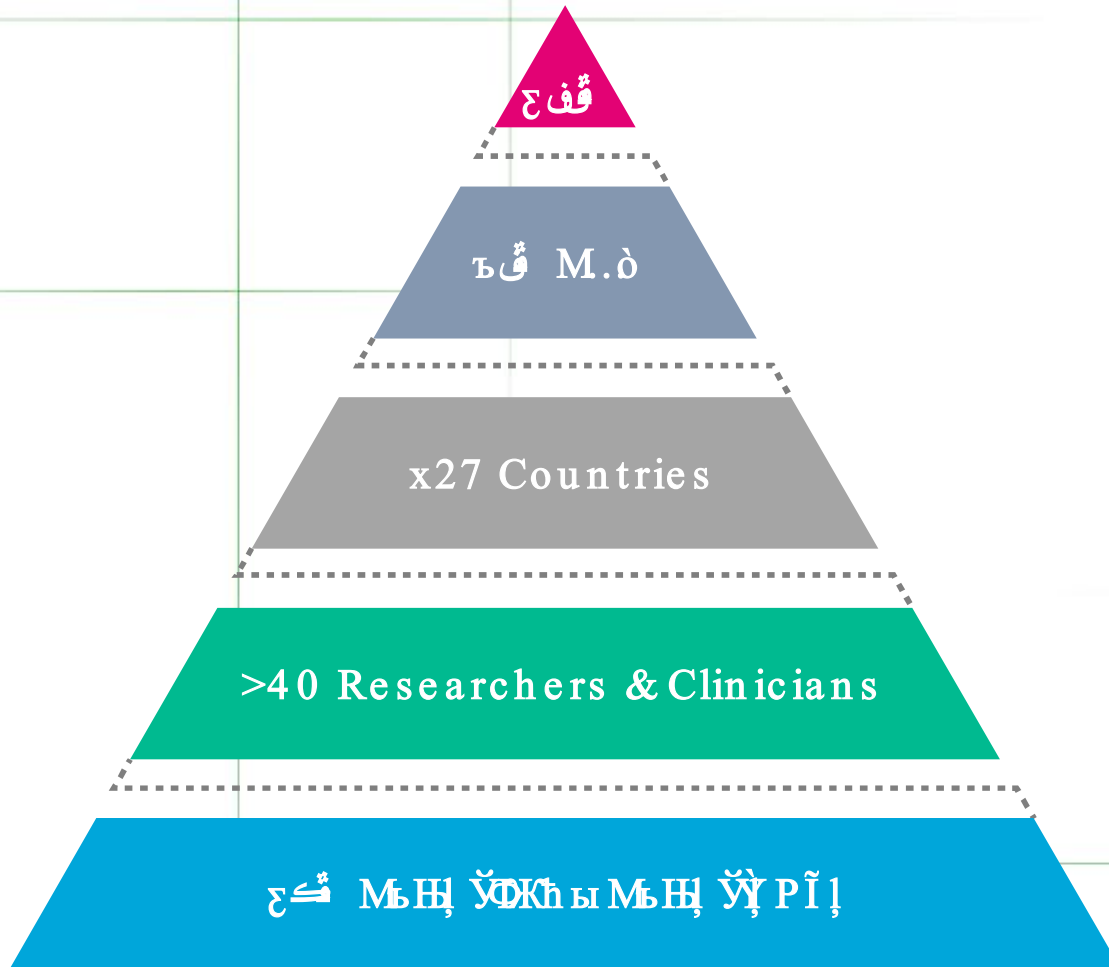
9 Non-EU MS incl. Australia, Canada, Ethiopia, Georgia, Nepal, Serbia, Switzerland, UK and USA.

>40 Researchers & Clinicians

Researchers, Psychologists & Medical Experts: >40

ERN ReConnect, ERN GENTURIS, ERN eUROGEN, ERN ERNICA, ERN EYE, ENDOERN, ERN BOND, ERN EPICARE, ERN ITHACA & ERN Rare Liver

ERN ReConnect, ERN GENTURIS, ERN eUROGEN, ERN ERNICA, ERN EYE, ENDOERN, ERN BOND, ERN EPICARE, ERN ITHACA & ERN Rare Liver



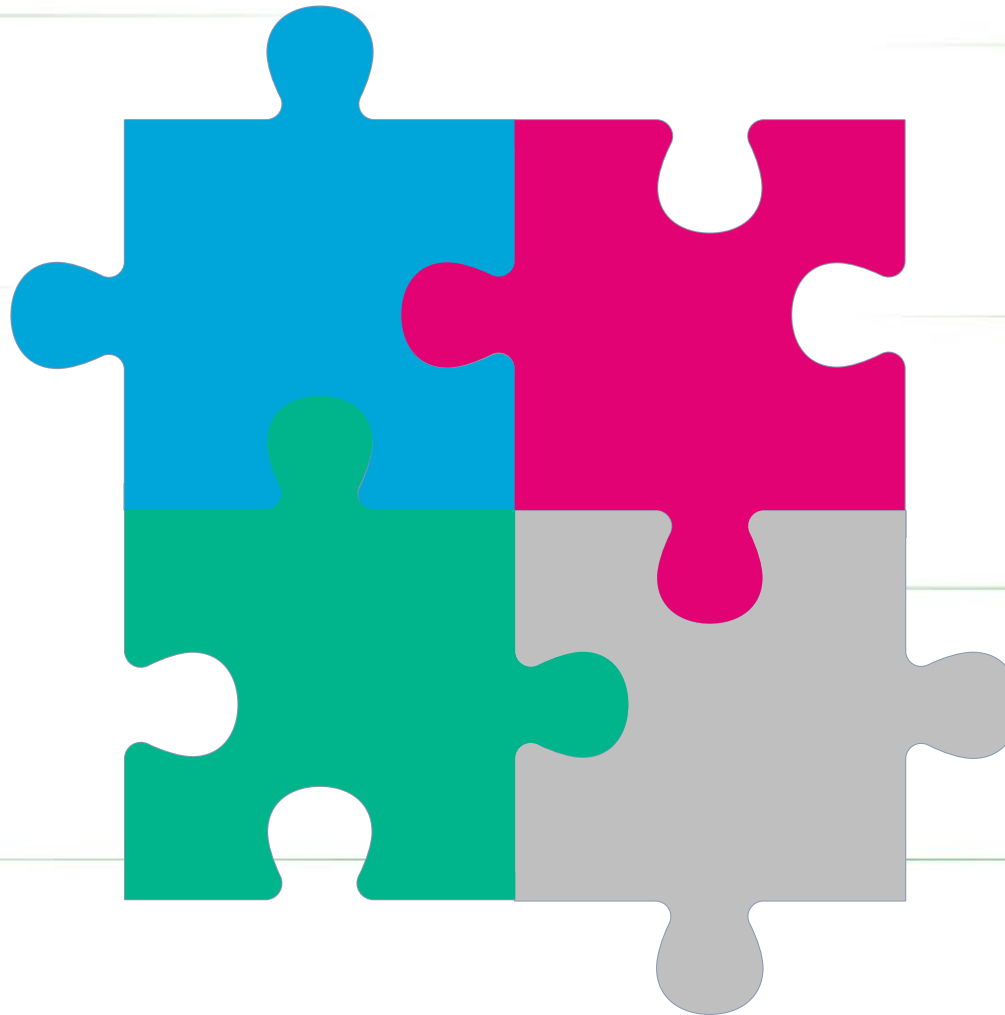
Partnership Network Governance

“ΦΙΥΡΓ ΓΉΒΗ

- Provide strategic direction, stakeholder engagement and workplans development
- Overseeing Working Group(s), agreeing upon priorities and action, reviewing progress and outcomes, to optimise Network impact.
- Approval Network membership applications.

“ΦΑΙ ΨΗΕΙ ΨfήΨΟ

- Share developments with all the Network Members
- Communication activities
- Consultation and feedback on network strategy and work plans



Population Needs & Advocacy WG1

- Co-creation of an Update Position Paper and draft articles and publications on needs
- Scope RBV Survey on Mental Health
- Peer-learning programme
- Coordination of communication to raise awareness of the impact of RD on MH.

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- Coordination of research activities including literature reviews
- Identification of existing best practice, resources and tools to creation of a Mentally Healthy Toolkit
- Co-development of Clinical Protocols, Standards of Care and Pathways

Community Representatives



Claas Röhl
Neurofibromatosis T1&T2
ERN GENTURIS



Diana Kwast-Hoekstra
ENDO-ERN



Zhana Chokheli
Rare Epilepsy
ERN EPICARE



Dorica Dan
Prader Willi Syndrome
ERN ITHACA



Eva Schoeters
Tuberous Sclerosis
ERN ITHACA



Diana Marinello
Researcher
ERN ReCONNECT /
ERN RITA



Rebecca Tvedt Skarberg
Osteogenesis Imperfecta
ERN BOND

Clinicians / Researchers Representatives



Lucy McKay
General Practitioner
Medic4Rare Diseases



Leticia Pias
Paediatric
Neurologist



Francesc Palau
Paediatric
Geneticist



Sara Talarico
Scientific Lead
ERN ReCONNECT



Caterina Grano
Anorectal Malformations
ERN ERNICA / eUROGEN



Andre Rietman
Psychologist
ERN ERNICA



Lauren Roberts
Rareminds

Role: Oversee the strategic development of the network and implementation of the annual work plan and advise on emerging issues and future priorities.

Number: 14 Members with a balance of patient representatives & clinicians / researchers

Meetings: Network will meet x4 per year

EURORDIS Mental Wellbeing Partnership Network

Steering Group Terms of Reference June 2023

The Steering Group will oversee the strategic development of the network and implementation of the annual work plan and advise on emerging issues and future priorities.

It will do this by:

- ensuring appropriate engagement of stakeholders including the wider public, people with lived experience, service users, families and carers.
- providing overall strategic direction, including supporting the development of the workplans and strategies to drive implementation for the duration of the EURORDIS Mental Wellbeing Initiative.
- overseeing the work of the Working Group(s) of the Partnership Network, agreeing upon priorities and action, reviewing progress and outcomes, to optimise the Partnership Network impact.
- approving Network membership applications.
- sharing learning and good practices on improving mental wellbeing.
- ensuring that all members are acting as advocates for the broader aims and aspirations of the Partnership Network.

The Steering Group will be comprised of approximately 10 members appointed by EURORDIS for an initial term of 2 years, with the possibility of renewal. These members will consist of the two co-chair of the Partnership Network and the lead and co-lead of the Working Group(s). The selection process to sit on the Steering Group will strive for balanced representation of the Partnership Network participants, with respect to sector and stakeholder group – experts by lived experience, clinicians and policy leads; and connect with social, educational and employment experts from the EURORDIS Social Pillar Advisory Group.

Steering Group decisions will be made through consensus of committee participants. The Steering Group will be chaired by the two co-chairs, one co-chair from the EURORDIS Board of Directors and the other co-chair will be the EURORDIS Mental Wellbeing Lead.

Επιχειρησιακό σχέδιο για την υλοποίηση του έργου

All Stakeholder Meeting #2
- 17/Jan/24

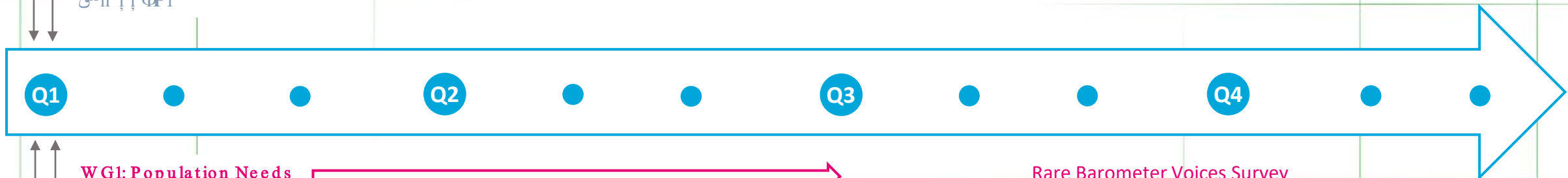
«Επιχειρησιακό σχέδιο»
πρόγραμμα υλοποίησης

! Ημερίδα για την υλοποίηση του έργου
στη Γενική Συνέλευση

• 2η Συνέλευση

• 3rd Meeting

All Stakeholder Meetings #4



WG1: Population Needs & Advocacy
1st Meeting: 15/Feb/24

1η Συνέλευση για την υλοποίηση του έργου
στη Γενική Συνέλευση

Outline Position Paper

Gather Evidence

Rare Barometer Voices Survey

Co-creation Mentally Healthy Toolkit

Important Dates

- 1η Συνέλευση για την υλοποίηση του έργου - 15/2/24
- European Mental Health Week 2024 - 13-19/May/24
- 1η Ημερίδα για την υλοποίηση του έργου - 17/1/24

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