

# *Enhancing Mental Wellbeing in the Rare Disease Community*

EMM Satellite Workshop, Stockholm, 25.05.2023

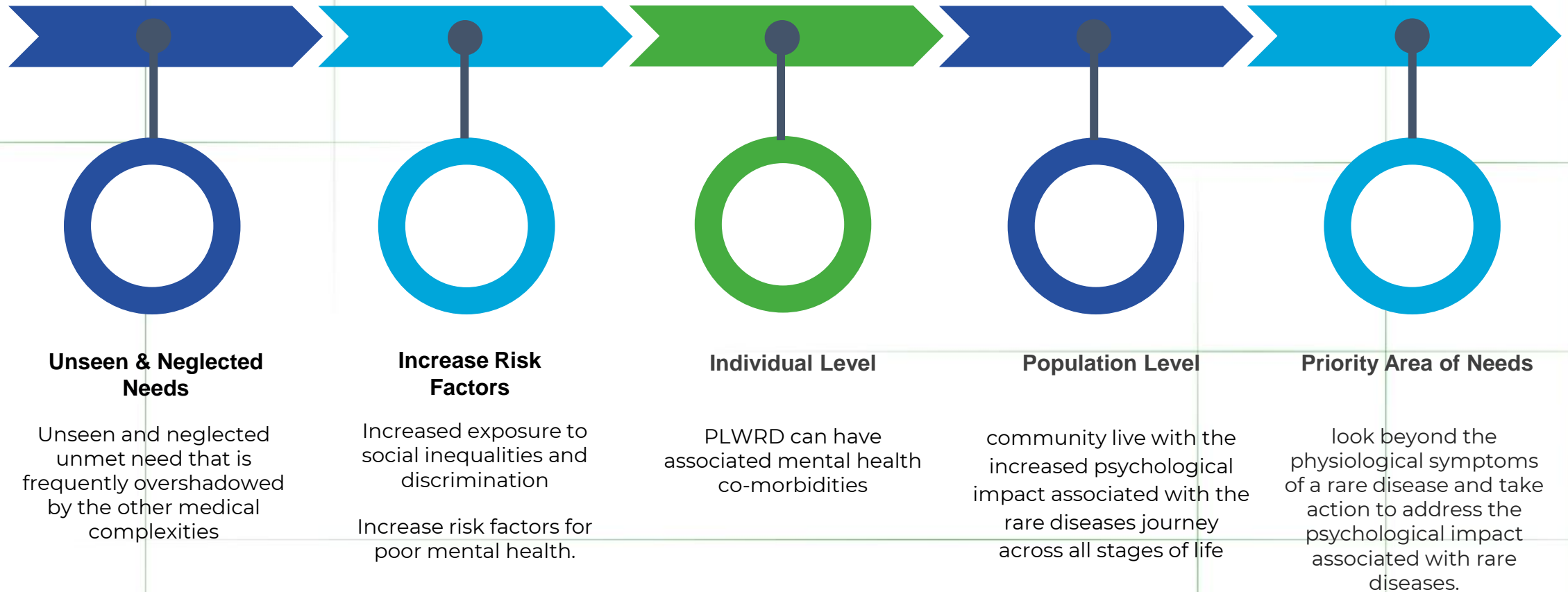




# Welcome & Opening Remarks



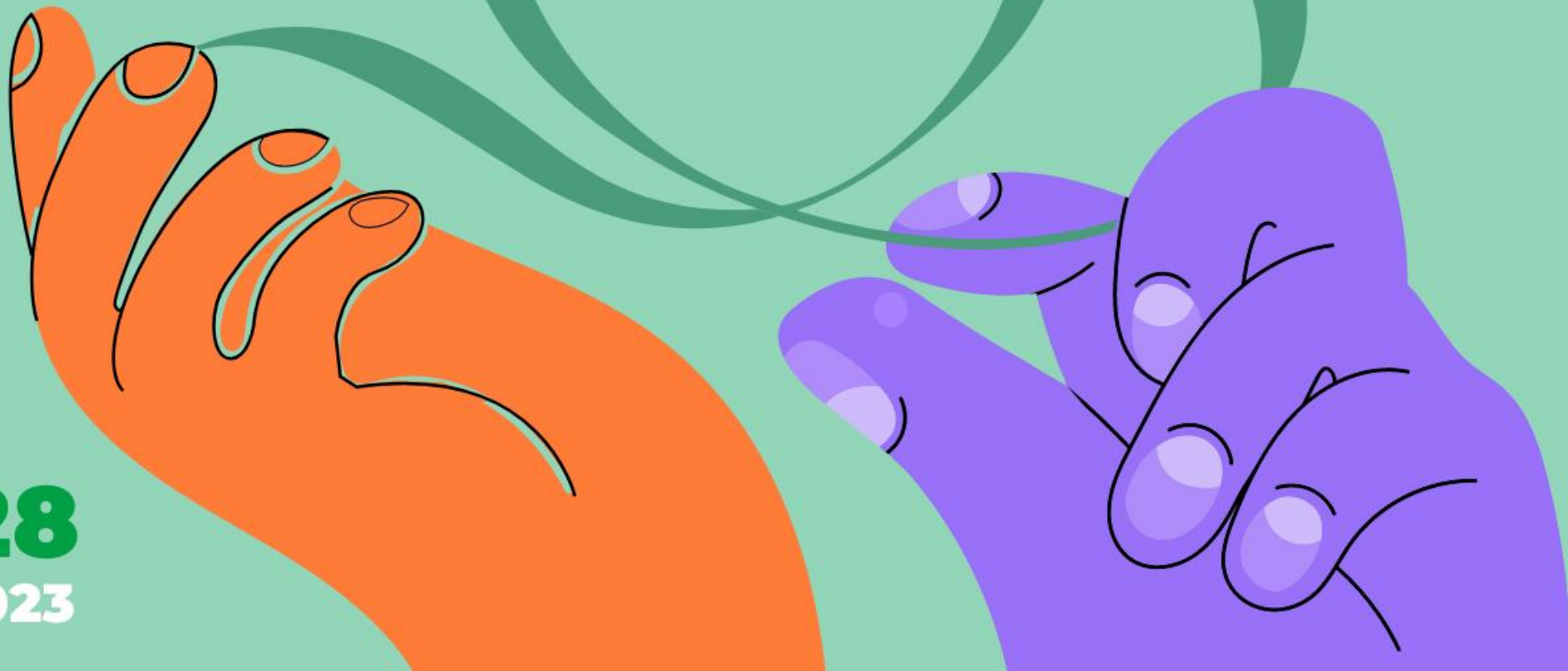
# Accumulative Impact on Wellbeing



# Mental health is universal and essential

#EuropeanMentalHealthWeek

#EMM2023



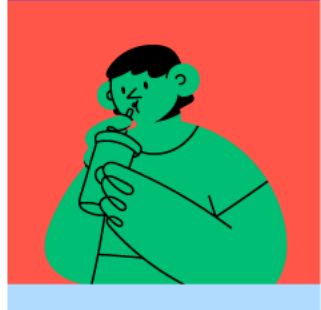
EUROPEAN  
MENTAL  
HEALTH  
WEEK

**22-28**  
**MAY 2023**



European Mental Health Week (EMHW) 2023 is the 4th Edition.

- Aligned with European Year of Skills, 2023 - vocational and digital skills, and **life skills for greater wellbeing**.
- Theme: **Mentally Healthy Communities. Thriving Together.**
- Aim: To **raise awareness and increase understanding mental health in different settings** (schools, workplace, communities) and at home so that everyone can thrive and flourish at every stage of life.
- **EURORDIS Support:** EMM Satellite Workshop & Networking Session on Enhancing Mental Wellbeing are registered as official EMHW Events.



# Workshop Principles

## Everyone Participates

- Only shared your personal experience if you feel comfortable

## Share 'Air Time'

- Listen to other people without interrupting

## Respect Difference

- Be respectful of other people's views and opinions

## Support Each Other

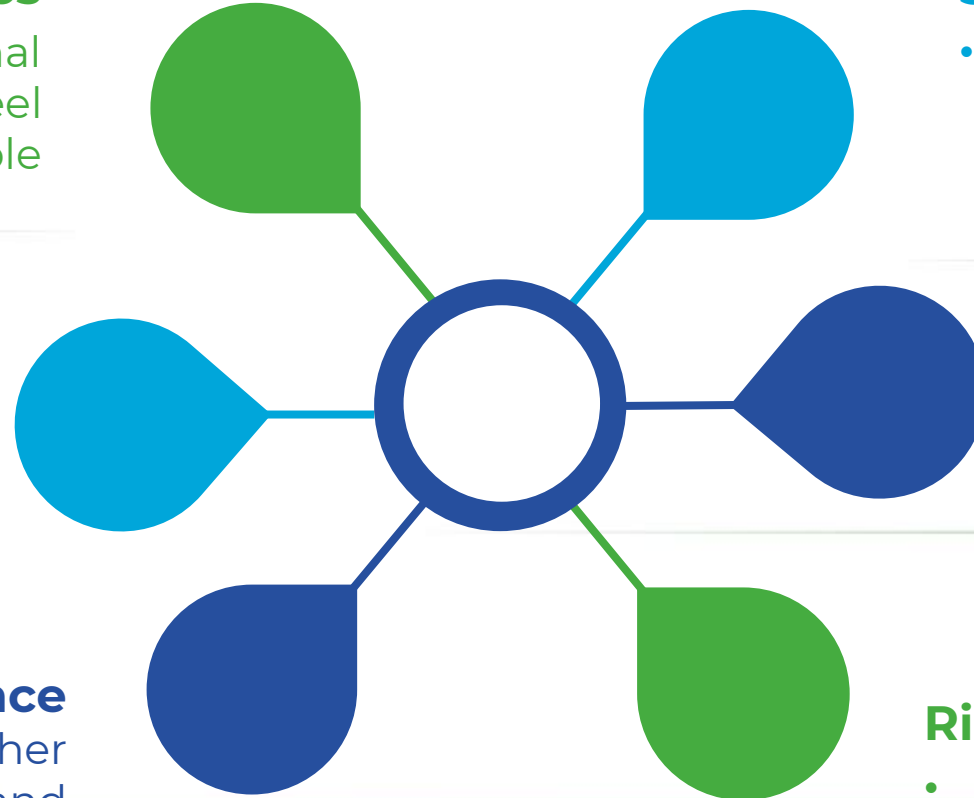
- Be Supportive rather than judgemental

## Confidentiality

- Don't use any personal information outside the workshop

## Right To Step Out

- Please notify one of the Team if you wish to step out of the workshop



# Workshop Team



Kym Winter

Rare Minds



Susanne Blichfeldt

International  
Prader-Willi  
Syndrome  
Organisation



Claas Röhl

NF Kinder & NF  
Unite



Kirsten Johnson

Fragile X Society /  
EURORDIS



Concha Mayo

EURORDIS



Rita Francisco

EURORDIS



Ines Hernando

EURORDIS



Matt Bolz-Johnson

EURORDIS

Workshop aims **to develop an understanding on how rare conditions impacts the mental wellbeing** in all aspects of daily lives.

Through group discussion, we want to **identify what has worked (and has not worked) to help to support their mental wellbeing** that can ensure that everyone can thrive and live a full life.





# Agenda

Time	Topic	Speaker
14.00 – 14.08	Welcome & Opening Remarks	Kirsten Johnson, Fragile X Society
14.08 – 14.20	Defining Mental Wellbeing	Matt Bolz-Johnson, EURORDIS
14.20 – 14.35	Impact of Mental Wellbeing on Rare Diseases	Kym Winter, Rare Minds
14.35 – 14.55	Case Study: Prader Willi Syndrome	Susanne Blichfeldt, IPWSO
14.55 – 15.15	Case Study: Neurofibromatosis	Claas Röhl, NF Kinder & NF Unite
15.15 – 15.25	Questions & Answers	Kirsten Johnson, Fragile X Society
15.25– 15.50	Coffee Break	
15.50 – 17.50	Breakout Groups	All
17.50 – 18.00	Next Steps & Closing Remarks	Kirsten Johnson, Fragile X Society

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



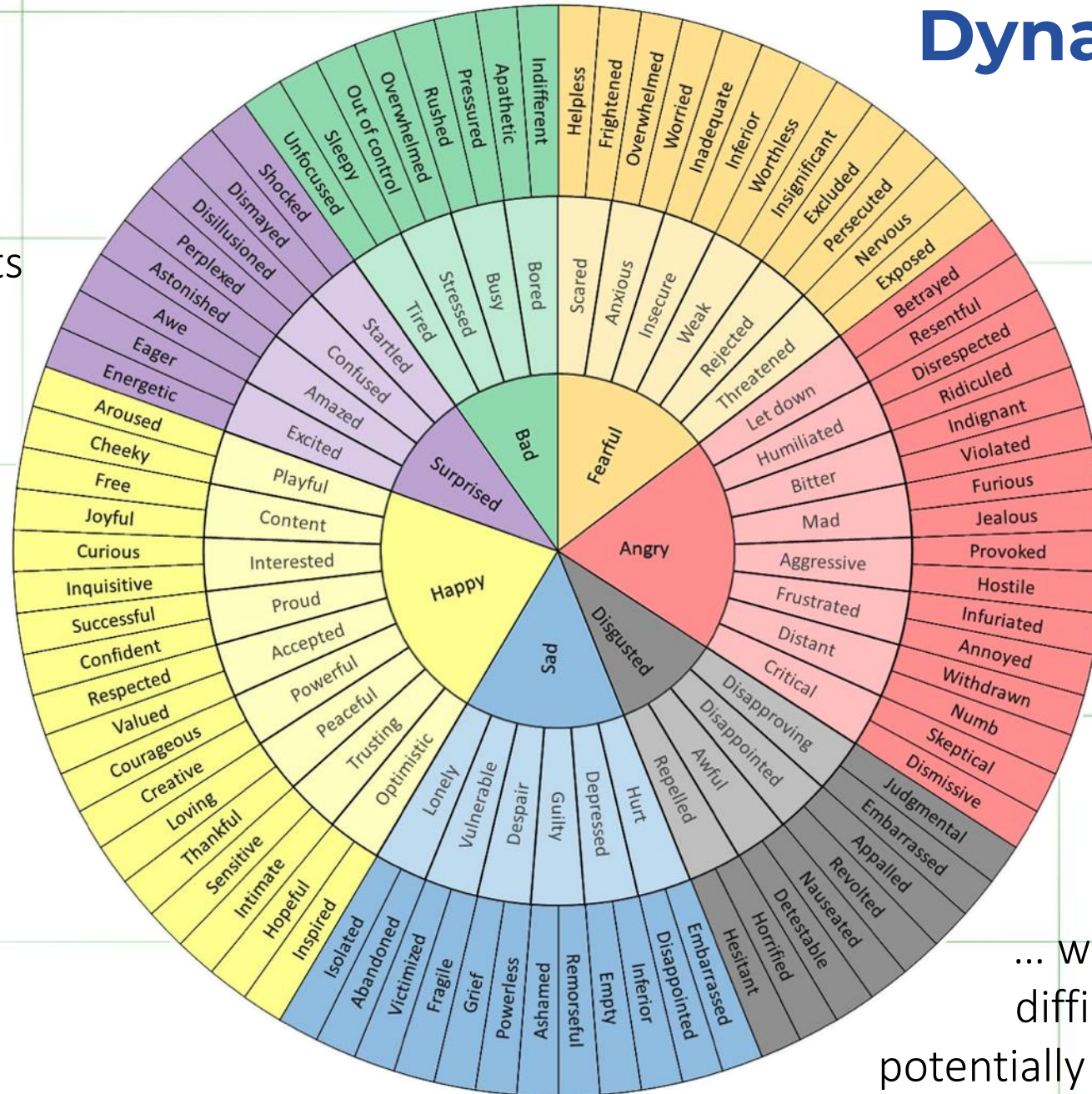
# Defining Mental Health



# Dynamic State of Wellbeing

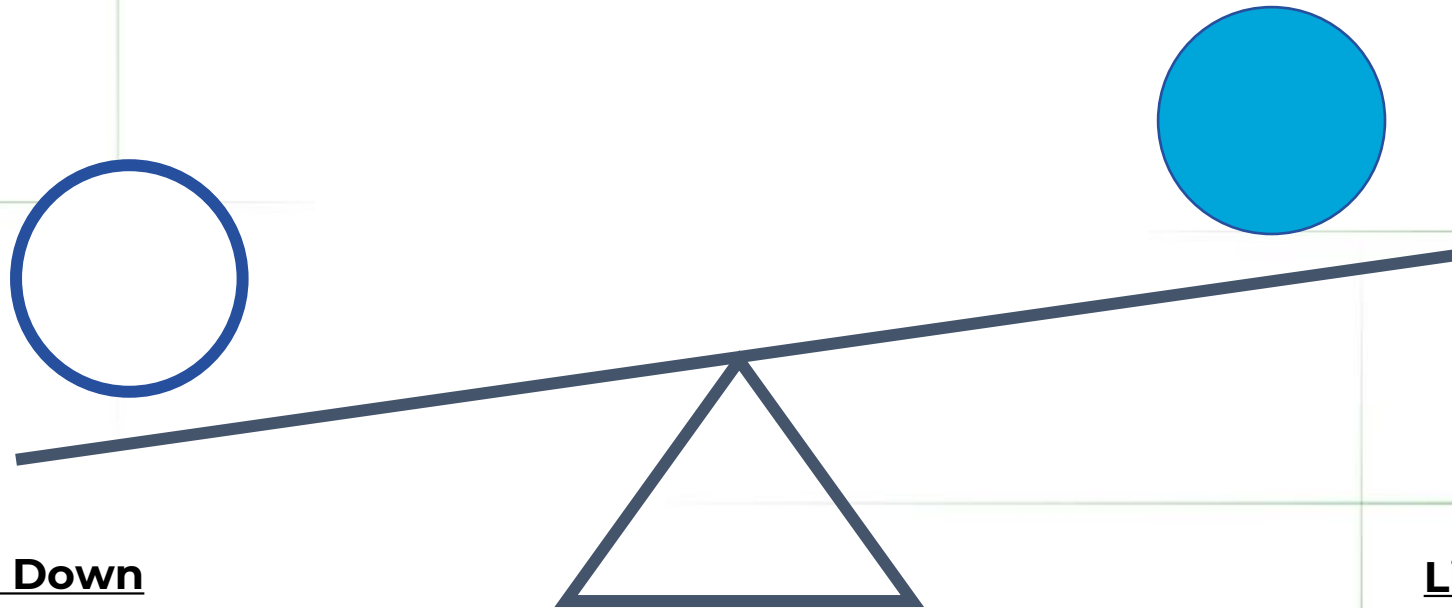
Mental Wellbeing exists on a **complex continuum...**

... and is experienced differently from one person to the next...



... with varying degrees of difficulty and distress and potentially very different affects.

# What Lifts Us Up or Brings Us Down?

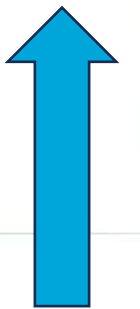


## **Brings Us Down**

- Judgement
- Expectations
- Difficult Relationships
- Chronic, Intense & Sustained Stress

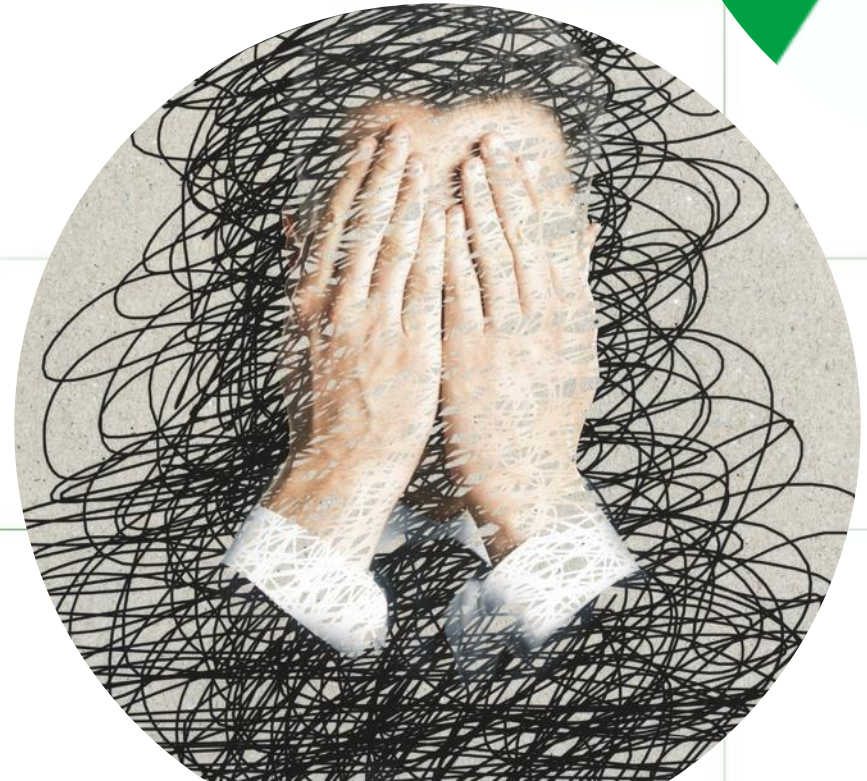
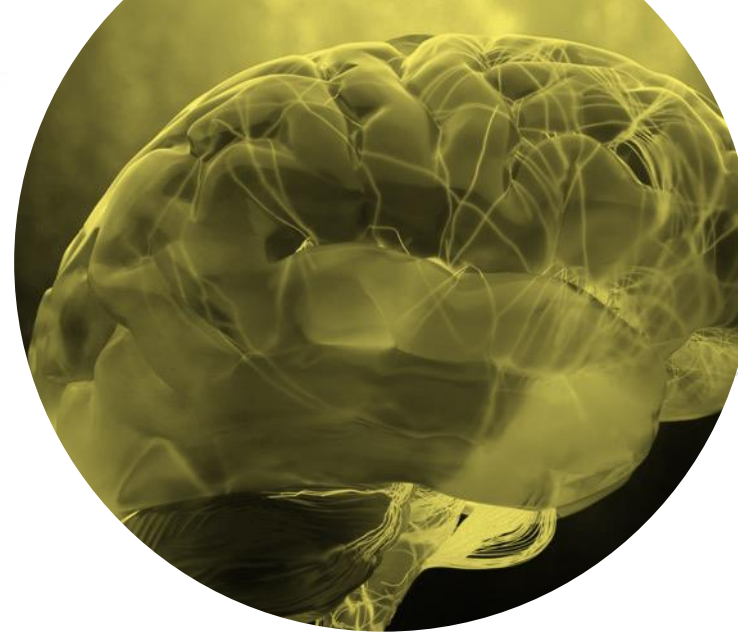
## **Lifts Us Up**

- Music, Gardening, Exercise & Sleep
- Friendship & Socialising
  - Breaks & Holiday
- Good Stress e.g.: small amounts



# Awareness of Stress

- A state of worry or mental tension caused by a difficult situation.
- Normal and helps us to meet our daily challenges and motivates us to reach your goals.
- Sustained stress impacts on mental fatigue and burn out.
- Effectives us all in different ways and our ability to deal with stress varies from person to person.
- Stress container, stress signatures and different strategies.



# What is Mental Health?

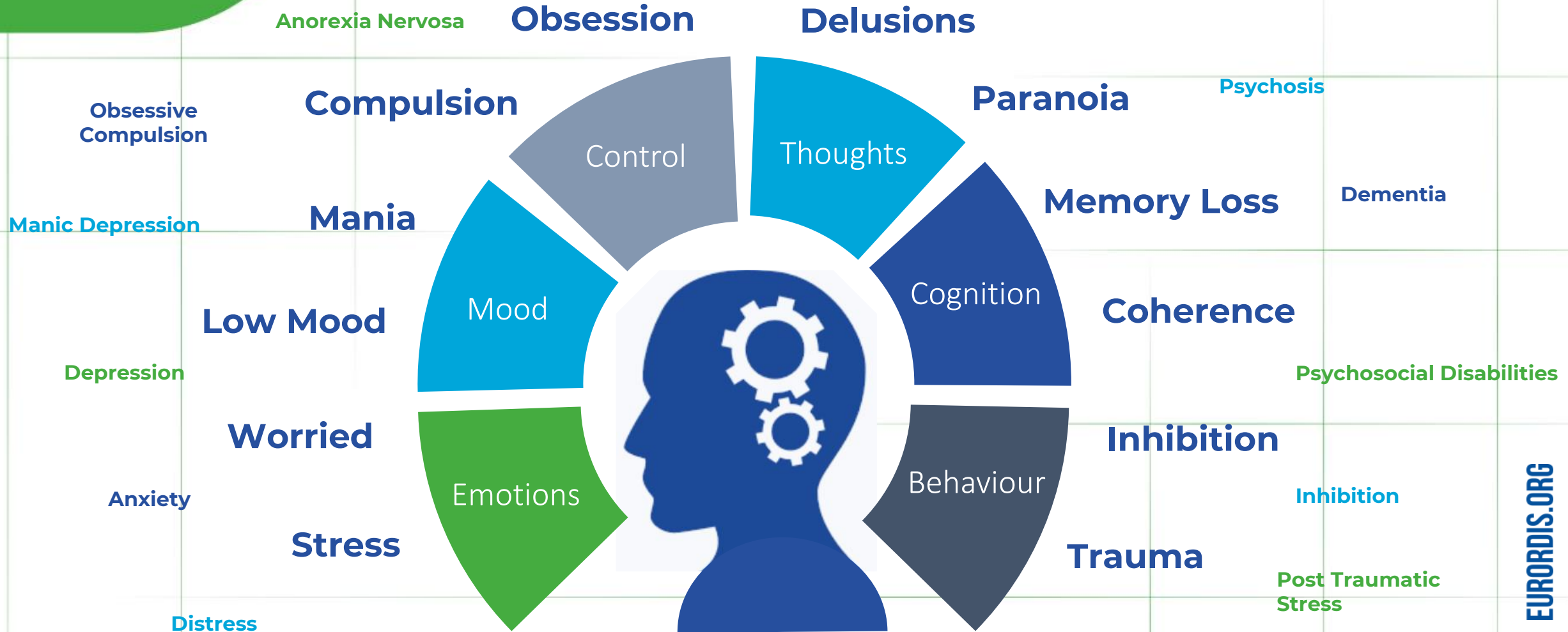
**Mental health is a basic human right. Mental health is defined as:**



**“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.”

# Symptoms of the Mind



Functions → Experience → Symptoms

# When does an experience become a symptom?

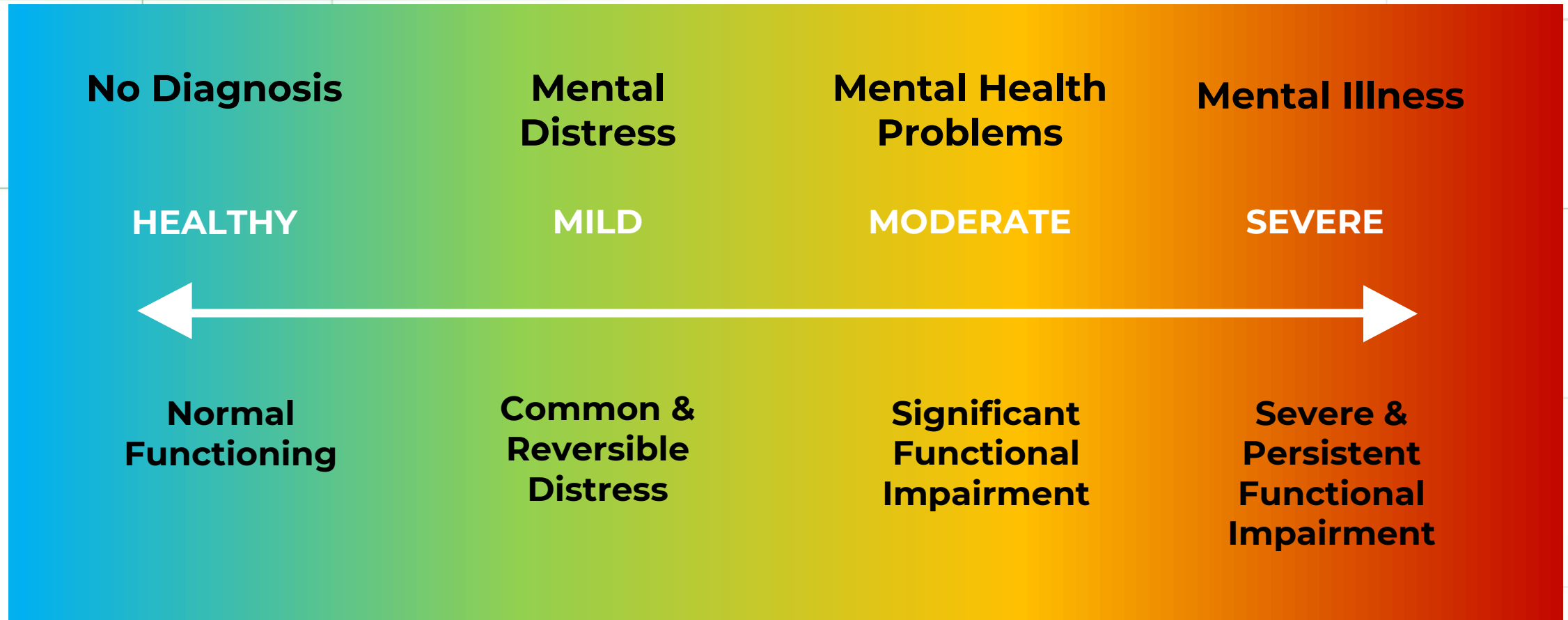
Who is bothered by it? Subjective experience as different people / families have different tolerance.

When does an experience become a symptom?

- Severity
- Distressing (to the person or those around them)
- Affect functioning
- Longer in duration
- Out of context and socio-cultural norms



# When does an experience become a symptom?



# Risk Factors and Determinants

Bio-psychosocial, economic and environmental determinants may combine to protect or undermine our mental health and shift our position on the mental health continuum.

Protective factors serve to strengthen resilience.



# Risk Factors & Determinants

## Biological

- Genetics, injury, infections
- Brain lesions, neurological problems
- Hormones, steroids, blood sugar, thyroid imbalance
- Surgery, treatment

## Psychosocial

- Trauma, violence, adverse life events, stress
- Negative social media
- Health behaviours

## Economic

- Poverty
- Cost of living
- Ability to work and live independently

## Environmental

- Experience of prejudice
- Humanitarian emergencies
  - Forced displacement
  - Climate crisis

# The Power of Language



Words have a big influence on how we think and act.

- The way we talk about mental health can hurt, discriminate, and reinforce negative stereotypes, without us even realising it.
- De-stigmatisation in the field of mental health begins with the use of words, that is, with semantics.

Preferred terms take into account all factors contributing to a lack of wellbeing:

- Mental distress / Difficulties / issues
- Co-creation instead of co-production



Source: MHE published "[The Power of Language](#)," a glossary of mental health terms to help fight this stigma.

# Mental and Physical Health are intrinsically linked

What is good for physical health is good for mental health serve to strengthen resilience:

- Positive social interactions
- Activity and consumption
- Quality education
- Decent work and work-life balance
- Community, quality relationships and support
- Safe neighborhoods and community cohesion



# Proud to support

M·H·E  
Mental Health Europe



## Thank You

#EuropeanMentalHealthWeek

**22-28**  
**MAY 2023**



EURODIS STOCKHOLM MAY 2023

Kym Winter

Rareminds

# Impact on Mental Wellbeing of Rare Diseases



# 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

# 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

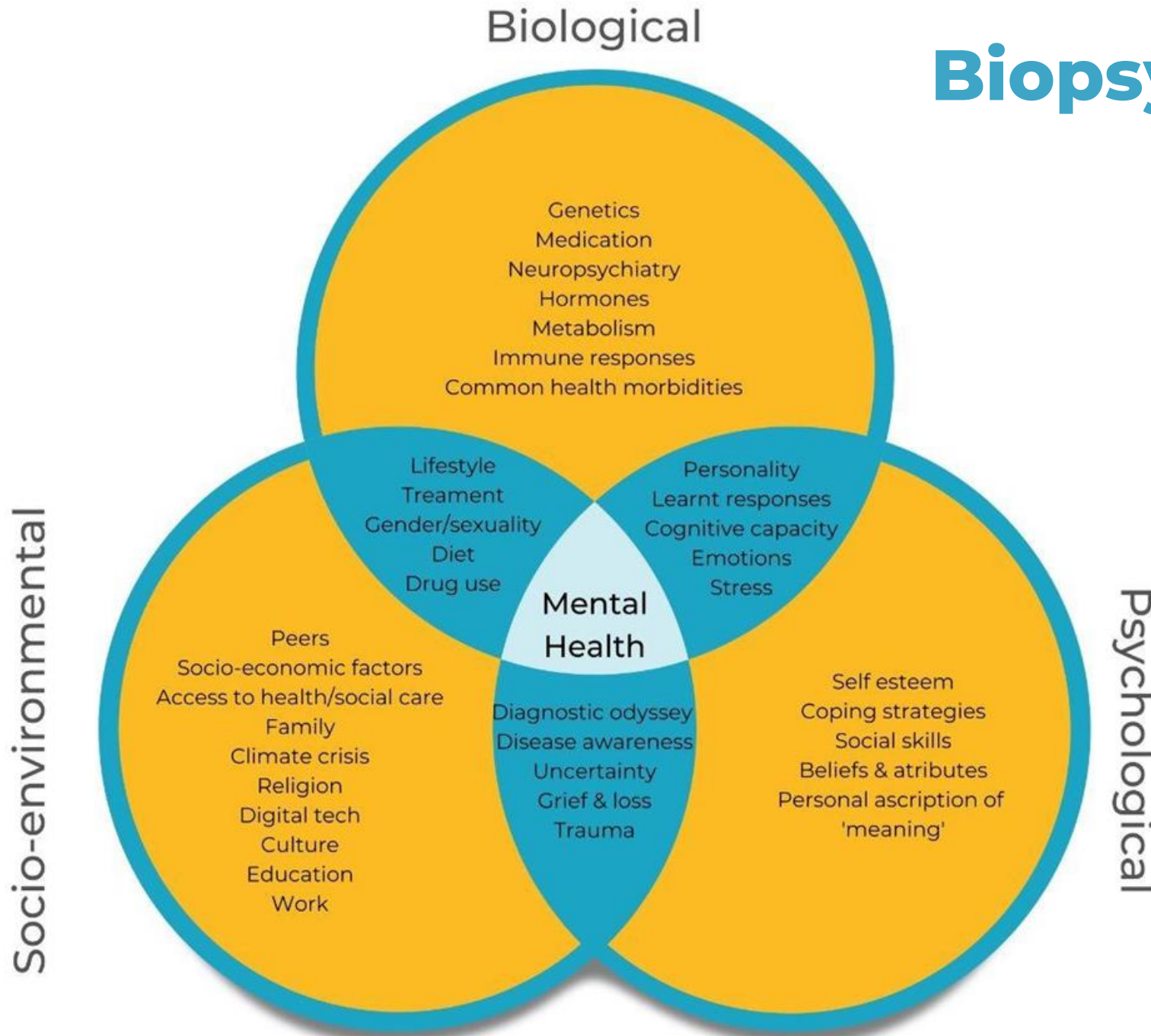
70% have felt at breaking point

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 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'

#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).

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

**Thank you**

rareminds  
Mental Health for the Rare Disease Community





EURORDIS STOCKHOLM MAY 2023

Susanne Blichfeldt MD

Denmark



## Case Study: Prader Willi Syndrome & Associated Mental Health Co-Morbidities

# Prader-Willi Syndrome (PWS)

- 1:15.000 newborn
- Both sexes, all countries
- Not inherited
- Re occurrence : usually not, only few at risk
- Prenatal diagnoses is possible, but the disease is not expected, not looked for
- Postnatal DNA test possible, but not included in newborn screening programs
- PWS is caused by missing genetic signals from the paternal chromosome 15
- Either by deletion of paternal chromosome 15q, or uniparental maternal disomia of chromosome 15 or imprinting defect on paternal chromosome 15q (rare)
- Parents are healthy, no diseases during pregnancy, no ones fault!

# PWS is a genetic disease, affecting brain development

- The PWS “missing gene expression” on chromosome 15q11-13
- Magel2 -- Necdin IC --SNORD116-- SNORD11
- These genes are responsible for :
  - Nerve Cell Growth and Cells Migration in the brain
  - Affect hypothalamus and related areas, also brain frontal lobe
- This can explain many of the behavioral and cognitive problems/symptoms
- And also the treatable hormonal deficiency



# The missing genes can explain many symptoms

- Physical symptoms
- Hypotonia
- Hormone deficiency
- *Pain registration, the high pain threshold*
- *Temperature regulation and sensation*
- *Sleep regulation*
  
- Behavior and mental health symptoms
- Hyperphagia
- Autism Symptoms, Understanding, Reactions and " all behavioral problems "
- Skin Picking

# Treatable hormone deficiency in PWS

- The hormonal deficiencies are caused by hypothalamic dysfunction
- Growth hormone deficiency treatment:
- Can start during infancy : daily injections
- Helps growth: height and muscles and motor development and organ function: recommended to be continued in adulthood
- Sex steroid deficiency treatment
- Individual needs: can start early in pubertal years if needed
- girls: estrogen
- boys: testosterone

# PWS. Clinical symptoms

- Newborns:
  - Severe hypotonia, cannot suck, need tube feeding, no crying, sleepy.
- Next months:
  - gradually improving: eating, moving, contact
- 1 year old: can sit, can eat, babble, looking at food.
- Weight OK

2



FIRST DAYS

# The first years

- Gradually motor improvement: walk at 2-3 years old or later
- Speaking: improves, delayed but great variation,
- Cognition: variation: mildly to moderately delayed
  
- Social interaction: difficult,
- Enjoy company but difficult to follow other children's play without adult support.
- Often regarded as a mild and easy child, can sit alone for long time
- Playing by themselves, simple role plays, can be repetitive, wanting own rules.
- Need a structured day. Too many changes can be difficult for the child



# School years

- Motor development improves, still hypotone, walking OK, balance is weak
- Language much better, some have speech problems,
- Cognition: Great variation.
- Many learn to read and write. Thinking is concrete but
- In spite of being talkative. understanding can be poor.
- Social interaction:
- With support and with realistic expectations the child can participate
- Autism spectrum traits. Poor understanding of own social capacities

# Teen age years

- School:
- with good support, and realistic expectations, the young one can learn and enjoy
- Sport: Swimming, horses, etc. can be in a group, and enjoy
- Friends: difficult to understand others feelings, many prefer own activities
- Girlfriend/boyfriend: wants to have, many have one “to be with”, send sms and kiss but often we see that interests in sexual relationship is rare.
- Risk: Sexual abuse. Paid with food.
- Social media: can create difficulties, risks of “bad contacts”
- Often a difficult time. Especially if there is less food control, behavior difficult



# Late teen age years

- Preparing for the next years:
- Few possibilities in many countries:
- Boarding schools must be avoided:
- Because: no food control, weight goes up , 30 kg in few months is seen
- Work: can participate, when a task is structured, can be very precise
- But food control is still needed.
- The years where future must be prepared: where to live, job etc

# The most striking difficulty for the child

- No normal sensation of appetite and satiety.
- Gradually after age 1-2 years a peculiar interest and drive for eating is seen.
- It is not a normal hunger, but many think so, and give food
- Without support gradually a severe obesity develops
- Without early intervention and learned regulation, temper tantrums can arise, if there is no plan for meals, when food is denied or not regulated.
- Therefore many parents can not resist
- The drive for eating persists, but overweight can be avoided.
- The child can learn the system, and the adult still needs support

# The other difficulties the child has

- Social interaction:
  - Enjoys to be part of the group, but cannot interact as others.
- Some of the causes are:
  - Cannot understand facial expression and voice levels
  - Cannot understand other children´s emotions
- Sudden changes of plans or rules in a play is very difficult
- Need to know what is going to happen, otherwise anxiety arises

# And more problems

- Perseveration.
- The ability to stop. In many situations:
- The small child can sit for a long time with a toy, and wants the same toy every day.
- Many need a clock- a timer to know when a situation stops
- Collecting: dolls, video, also things for us without meaning
- Asking questions: have heard the answer many times, but ask again
- Temper tantrums and screaming and crying: cannot stop when asked to.
- The child see the negative reactions, and cannot stop.
- All this is caused by a not normal prefrontal cortex in the brain

# Fantasy and reality

Small normally developing children can think their fantasy is a reality

This can persist in PWS, also in adulthood

This can cause harmless storytelling,  
but can also bring the family into trouble

# The need for structure and plans

- What happens when there is not a rule or a plan:
- The child and adult with PWS create “ his own rules”
- “Rules” that we do not know about
- And then when these rules are not followed, the child/adult becomes angry
- A rage can occur
- Also if you want to change habits, can be a problem : example: with hygiene

# What has brain scans learned us

- In many situation we see in brain scans which ares of the brain that are active.
- And we see what happens in PWS:
  - Can be:
    - When looking at food.
    - When sudden changes during the day occur
    - In a rage.
    - Other areas in the brain are activated, than normally seen

# What do parents and others need to know

- Hyperphagia and risk of obesity is only top of the iceberg
- PWS is a disease affecting the brain, caused by missing gene signals.
- Behavior is the most demanding, beside food control
- You can do a lot to help the child to live a happy life
  
- Food control: like in diabetes and allergy, but more demanding
- Plans for activities and social interaction
- Learn appropriate behavior and rules for hygiene
- Have a lot of activities, planned, have fun, be with animals. Enjoy!













EURODIS STOCKHOLM MAY 2023

Class Röhl

Austria

# Case Study: Neurofibromatosis Type 1, Associated Mental Health & Neurological Co-Morbidities





**Being a  
Dad  
&  
Becoming  
A Patient  
Advocate**

# Being a Dad - becoming a patient advocate





# About NF1

## What is Neurofibromatosis Type 1?

- Genetic tumour predisposition syndrom
- Incidence: about 1:2.200-1:2.500
- 5 children with NF1 are born every day in the EU
- Heterogene and complex disease - ***the disease with the 1.000 faces***
- 50% of the affected people have healthy parents - spontaneous mutation
- No cure
- Treatment of the different symptoms is often challenging and not satisfactory for patients

Typical Cafe au lait spots are usually the first clinical sign of NF1

# About NF1

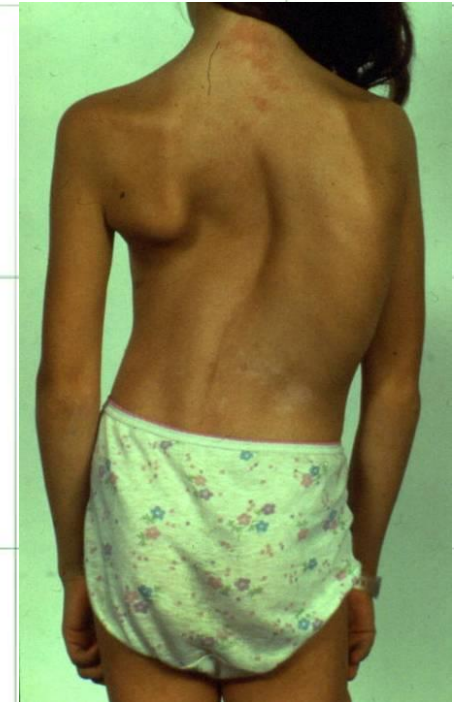


Typical Cafe au lait spots are usually the first clinical sign of NF1

# About NF1

## Challenges of living with Neurofibromatosis Type 1?

- NF1 is very unpredictable - throughout life there are different health threats (including different cancers)
- NF1 can cause disfigurement (due to tumours or bone manifestations)



# About NF1

## Challenges of living with Neurofibromatosis Type 1?

- Large plexiform neurofibromas are specifically challenging in terms of how they change a persons appearance. In about 13% of the patients, they can transform into malignant peripheral nerve sheath tumours with a very poor prognosis.



## Challenges of living with Neurofibromatosis Type 1?

- 80% of NF1 patients have neuro-cognitive deficits in at least one part of their cognitive functioning (ADHD, learning difficulties, behavioral difficulties, autism spectrum disorder, social functioning....)
- These difficulties can be easily misinterpreted by school staff - wrong decisions at school age can cause traumatic experiences for the children, and can have terrible consequences for their whole life
- Children with NF1 often have deficits in their motor functioning

Due to the visible manifestations but also non-visible challenges children with NF1 are often victims of bullying and are often excluded by their peers.

# About NFI

**People with NFI need specialized, multidisciplinary care -  
medical and psychosocial**

# Overview of QoL studies

## Online-Survey with 630 adult NF patients in USA (June-August 2020)

**91%** reported that NF has at least Some **impact on their quality of life**

**68%** would consider participating In a psychosocial trial

**52%** have a mental health diagnosis

**27%** believe that they have a mental health condition

Top treatment targets were: **anxiety, healthier lifestyle, and daily stress**

# Overview of QoL studies

## Depression Among Adults with Neurofibromatosis Type 1: Prevalence and Impact on Quality of Life

[Julie S. Cohen](#), ScM, [Howard P. Levy](#), MD, PhD, [Jennifer Sloan](#), PhD, [Jacinda Dariotis](#), PhD, and [Barbara B. Biesecker](#), PhD

[Link to study](#)

Females with NF1 have a significantly higher risk of developing depression

Current clinical guidelines.  
Only focus on medical aspects

Screening for depressive symptoms should be added to the list of standard management recommendations



# Overview of QoL studies

› J Eur Acad Dermatol Venereol. 2022 Aug;36(8):1359-1366. doi: 10.1111/jdv.18140.  
Epub 2022 Apr 28.

## Quality of life in neurofibromatosis 1: development and validation of a tool dedicated to cutaneous neurofibromas in adults

L Fertitta <sup>1</sup>, C Bergqvist <sup>1</sup>, M L Armand <sup>1</sup>, S Moryousef <sup>1</sup>, S Ferkal <sup>1 2</sup>, A Jannic <sup>1</sup>, P Ravaud <sup>3 4</sup>,  
V T Tran <sup>3 4</sup>, K Ezzedine <sup>1 5</sup>, P Wolkenstein <sup>1 5 6</sup>

The higher the burden of cutaneous neurofibromas the poorer the quality of life

[Link](#)

# Personalized psychosocial support & complementary therapies throughout life is needed

## Infancy

- Psychosocial support for family members
- Occupational therapy in case of developmental delays

## Preschool/ School-age

- **neuropsychological assessment**
- Social competence trainings
- MRI trainings
- Disease education
- Rehabilitation services

## Adolescence

- Transition program
- Building health competence
- Resiliency
- Selfworth
- Coping strategies
- Stress management
- Genetic counseling

## Adulthood

- Psychological assessment
- Psychological support
- Family planing
- Personalized support

# NF Kinder Services

## Diagnosis

## Preschool/ School-age

## Adolescence

## Adulthood

- Family guidance (virtual support program)
- NF Kinder center of expertise
- Access to information
- Peer to peer support

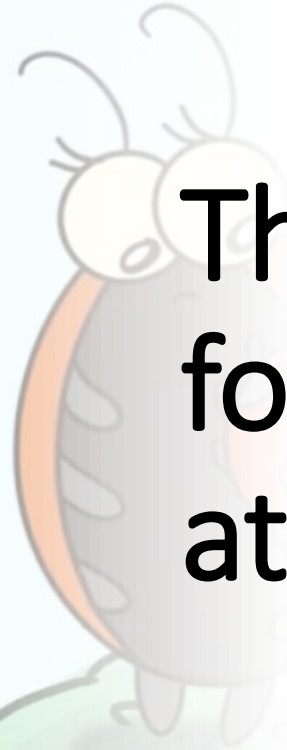
- **neuropsychological assessment**
- Social competence trainings
- MRI trainings
- Rehabilitation services
- Family weekends
- Peer to peer support

- **Neuropsychological assessment**
- Educational materials
- Rehabilitation services
- Youth weeks
- Social competence trainings
- Peer to peer support
- Patient conference

- Psychological assessment
- Peer to peer support
- Patient conference
- Access to on- and offline-information



Thank you  
for your  
attention!



# Coffee Break





# Breakout Groups

# Promoting Mentally Healthy Communities: using the World Cafe Approach

Time	Topic	Moderators
15.50 – 17.30	Breakout Groups Methodology  Room T2: <ul style="list-style-type: none"> <li>Breakout Group A1, A2, A3 &amp; A4</li> </ul> Room T3: <ul style="list-style-type: none"> <li>Breakout Group B1, B2, B3 &amp; B4</li> </ul>	Matt Bolz-Johnson
17.30 – 17.50	Reporting Back to Main Group	Kym Winter & Matt Bolz-Johnson
17.50 – 17.55	Next Steps	Matt Bolz-Johnson, EURORDIS
17.55 – 18.00	Closing Remarks	Kirsten Johnson

# Breakout Group Methodology

**World Cafe Approach** is a simple, flexible, and effective way to promote the sharing of ideas between different people.

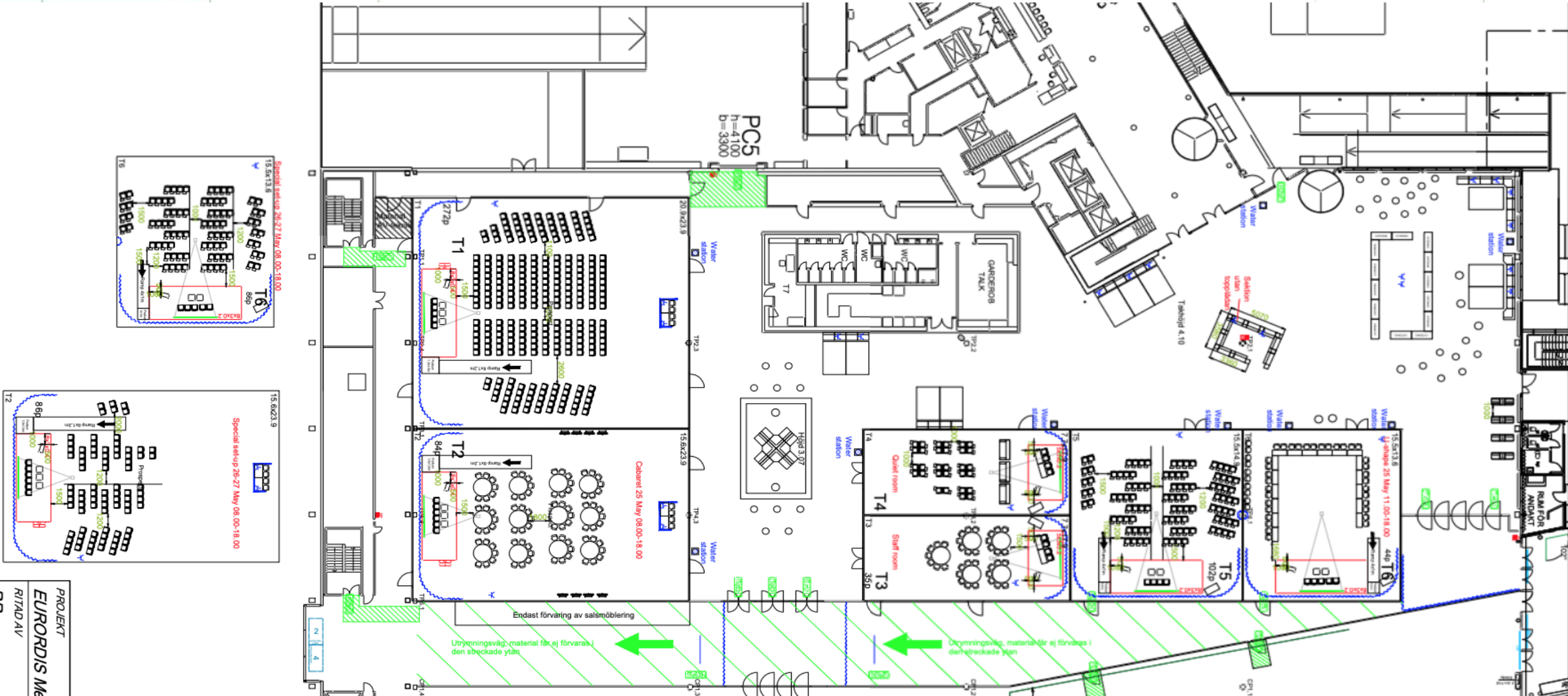
- **The main group will be divided into 2 Rooms – Room T2 & Room T3.**
- **In each room, participants are divided into four groups** to look at different aspects of the common unmet needs.
- **The groups, with the exception of the moderator, rotate** around to each table and comment on core unmet, identify existing best practices and identify policy actions.
- **Each group will spend 25 minutes per topic**, adding to the conclusions that the moderator has captured from previous groups. The findings will be recorded on flipcharts and summarised.
- **In the main group we will report back on each topic.**



# Breakout Topics

Topic	Moderators: Room T2	Moderators: Room T3
1. Diagnostic odyssey and access to treatment	Rita Francisco	Concha Mayo
2. Impact of living with a rare condition on identify and family relationships	Claas Röhl	Susanne Blichfeldt
3. Living with uncertainty and the impact of trauma	Kym Winter	Ines Hernando
4. Ability to access education, employment, and independent living	Kirsten Johnson	Matt Bolz-Johnson
<b>Reporting Back to Main Group at 17.30</b>		

# Room Layout



EUROPEAN  
MENTAL  
HEALTH  
WEEK

22-28  
MAY 2023



Unite for mental  
health and thriving  
communities

#EuropeanMentalHealthWeek



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



# Reporting Back

# Reporting Back

Feedback on the following topics:

1. Diagnostic odyssey and access to treatment
2. Impact of living with a rare condition on identity and family relationships
3. Living with uncertainty and the impact of trauma
4. Ability to access education, employment, and independent living

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# Next Steps

## Commission Communication on the Comprehensive Approach to 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.
- The new Communication is due to be published on 6 June 2023.
- Our specific goal is that rare diseases are seen as a vulnerable population requiring specific attention in the new Communication.



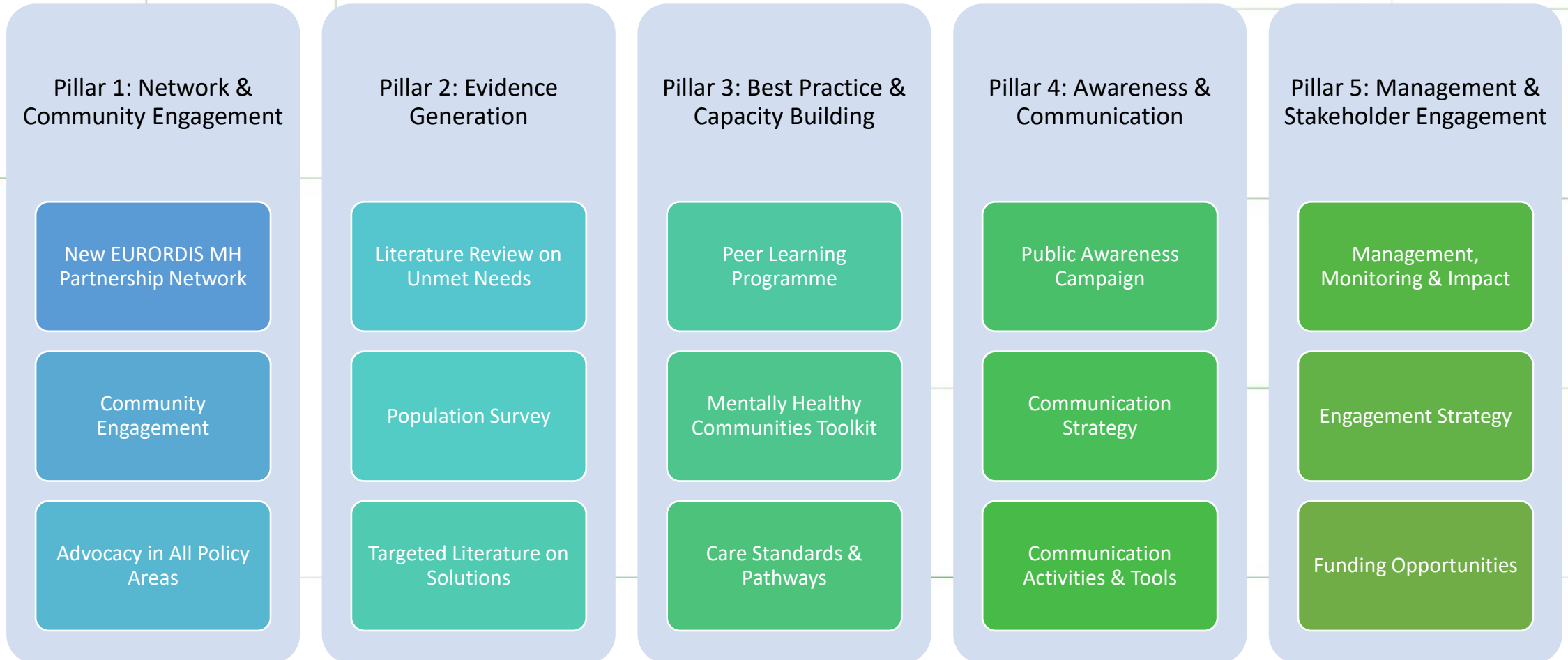
# EURORDIS Mental Wellbeing Initiative

Four-year initiative supported by a new EURORDIS Mental Wellbeing Partnership Network.





# Mental Wellbeing Initiative: Overview of the Structure



# New EURORDIS Mental Wellbeing Partnership Network

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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.





# Closing Remarks



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**Thank You**