



BOARD MEETING
BUCHAREST, ROMANIA
12-14 DECEMBER, 2024



Patient Workshop - Thursday 12 December

DETAIL PROGRAM - SESSION 2: PARALLEL SESSIONS

15H30 – 17H00

WORK GROUP 1 IDENTIFYING AND MAPPING RESOURCES TO BOOST FAMILY RESILIENCE

INTRODUCTION: IOANA STREATA, AMMI SUNDQVIST ANDERSSON

1. AMMI SUNDQVIST ANDERSSON, EPAG ITHACA, EPAG PERSPECTIVE ON FAMILY RESILIENCE, (10MN)
2. CONF. DR. IOANA STREATA, UMF CRAIOVA, ERN ITHACA, PROTECTING SUPPORTIVE RELATIONSHIPS / NETWORKS AT HOME AND AT WORK, (10MN)
3. DR. DAVID KRISTIAN BERGSAKER, FRAMBU RESOURCE CENTER FOR RARE DISEASES, FAMILY RESILIENCE/ EXPERIENCE IN WORKING WITH FAMILIES AT FRAMBU RESOURCE CENTER FOR RDS IN NORWAY, (10MN)

3 GROUP DISCUSSIONS: (45MN)

- . FAMILY RESILIENCE
- . REDUCING ISOLATION AND CONNECTING WITH OTHERS
- . PROTECTING SUPPORTIVE RELATIONSHIPS / NETWORKS AT HOME AND AT WORK

KEY NOTE AND Wrap up (15MN): DORICA DAN, MONICA BERTOLETTI & ANNE HUGON




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WORK GROUP 2 DIFFERENT FACES OF GRIEF

MODERATION: KASIA KATARZYNA ŚWIECZKOWSKA, GERRITJAN KOEKKOEK
FEW WORDS FOR EXPLORING ASSOCIATIONS WITH LOSS AND GRIEF (5 MN)

INTRODUCTION TOPIC : DR ANDRADA CIUCA (15 MN)

1. GERRITJAN KOEKKOEK - PARENTS' PERSPECTIVE, A SENSE OF LOSS IN THE LIFE OF THE PARENT OF A PERSON WITH A RARE DISEASE/DISABILITY, (6 MIN)
2. ESTHER SZABO- PATIENT'S PERSPECTIVE, EXPERIENCING LOSS, DEALING WITH EMOTIONS, (10 MIN)
3. DR MARIE - CHRISTINE ROUSSEAU - PROFESSIONALS' PERSPECTIVE, DEALING WITH YOUR OWN EMOTIONS AND EMOTIONS OF THE PEOPLE WITH DISABILITIES AND THEIR FAMILIES, (10 MIN)
4. SAMANTHA CARLETTI- LIFE AFTER LOSING A CHILD, (10 MIN)

DISCUSSION (25 MN) - HOW CAN WE, AS A COMMUNITY CONNECTED TO RARE DISEASES, SUPPORT INDIVIDUALS WITH DISABILITIES, THEIR FAMILIES, AND PROFESSIONALS IN COPING WITH LOSS AND GRIEF?

WRAP UP (5 MIN): KASIA ŚWIECZKOWSKA, GERRITJAN KOEKKOEK, JOLANDA VAN GOLD