



RARE
DISEASES
INTERNATIONAL

RDI Membership Meeting

26 MAY 2021,
14.00 - 17.00 CET (PARIS TIME)

UN RESOLUTION ON ADDRESSING THE CHALLENGES OF PERSONS LIVING WITH A RARE DISEASE AND THEIR FAMILIES (45 MIN)

STATE OF PLAY & TOOLS

CLARA HERVAS, RDI PUBLIC AFFAIRS MANAGER

WHAT TO DO AND WHAT HAS BEEN DONE

PANEL DISCUSSION AND Q&A

YANN LE CAM, RDI ADVOCACY COMMITTEE CHAIR & RDI COUNCIL MEMBER

ROBERTA ANIDO DE PENA, FADEPOF FEDERACIÓN ARGENTINA DE ENFERMEDADES POCO FRECUENTES (FADEPOF)

SAMUEL WIAFE, RARE DISEASE GHANA INITIATIVE

ELIZABETH VROOM, WORLD DUCHENNE

GLOBAL STATE OF THE ART RESOURCE (15 MIN)

INTRODUCTION TO GLOBAL SOA.

FEEDBACK FROM MEMBERS' CONSULTATION, WEBINAR AND SURVEY

FLAMINIA MACCHIA, RDI EXECUTIVE DIRECTOR

CHARLOTTE RODWELL, ORPHANNEWS PARTNERSHIPS, BUSINESS DEVELOPMENT & STRATEGIC COMMUNICATIONS

WHO COLLABORATIVE GLOBAL NETWORK FOR RARE DISEASES: KICK OFF THE SECOND CYCLE (30 MIN)

PRESENTATION OF THE CONCEPT: ARE WE GOING IN THE RIGHT DIRECTION?

MATT BOLZ-JOHNSON, RDI PROGRAMME DIRECTOR FOR THE CGN4RD

PANEL DISCUSSION: AND Q & A

MEOW KEONG THONG, MALAYSIAN RARE DISORDERS SOCIETY

MATT BOLZ-JOHNSON & FLAMINIA MACCHIA

PAPER ON ESSENTIAL MEDICINES LIST, THE WHO ESSENTIAL IN VITRO DIAGNOSTICS LIST AND IRDIRC ACCESS TASK FORCE (20 MIN)

DURHANE WONG-RIEGER, RDI COUNCIL CHAIR

CLOSING
MESSAGE (5 MIN)

LISA SARFATY, NATIONAL ORGANIZATION FOR RARE DISORDERS (NORD)

SOCIAL NETWORKING
(1 HOUR)

LET'S GET TOGETHER
CLICK ON LINK IN ZOOM CHAT

