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 PÉNA, 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, ORPHANEWS 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