Scientific Program

World Congress on

RARE DISEASES

DECEMBER 05-07, 2018 DUBAI, UAE



WORLD RARE DISEASES 2018

Conference Series llc Ltd
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Wednesday 05th December 2018 | **Day 1**

08:00-08:15 Registration Opens

Hall

08:15-08:30 Opening Ceremony

08:30-09:15

Keynote Presentation

Title: Drug delivery by tattooing to treat cutaneous leishmaniasis

Stef Stienstra, Royal Dutch Navy, Netherlands



09:15-10:00

Keynote Presentation

Title: Fighting rare diseases on a small island state

Michelle Muscat, The National Alliance for Rare Diseases Support, Malta



10:00-10:15 Networking and Refreshments Break with Group Photo

10:15-11:00

Keynote Presentation

Title: Understanding the patient and caregiver journey

Jennifer Mcnary, Rare Diseases Advocate, USA



Scientific Sessions: Rare Diseases | Infectious Diseases | Orphan Drug | Challenges in Rare Diseases | Living with a Rare Diseases | Rare Pediatric Diseases | Rare Haematology Diseases

Session Chair: **Stef Stienstra,** Royal Dutch Navy, Netherlands

Session Co-Chair: **Emmanuelle Logette,** Association francaise Sclerose Tubereuse de Bourneville, Switzerland

11:00-11:30

Title: The science behind what occipital horn syndrome

David Rose, Rare Revolution Magazine, UK

11:30-12:00

Title: Perioperative management of paediatric patients with genetic diseases

Yasser Zaghloul, Sheikh Khalifa Medical City, UAE

12:00-12:30

Title: Lymphedema: Update on diagnosis and management

Samer Ellahham, Regional Chair of Patient Safety Movement Middle East, UAE

Lunch Break 12:30-13:30 @ Restaurant

13:30-14:00

Title: Liver stiffness predicts relapse after direct acting antiviral therapy against chronic hepatitis C virus infection

Ali A Ghweil, South Valley University, Egypt

Special Sessions

14:00-14:45

Title: Recent updates in sickle cell disease, cardiac amyloidosis and hemophilia

Mert Ceyhan, Pfizer, UAE

Workshop 1

14:45-16:15

Title: Rare disease PRO registries – Empowering patients to advance research

Ginger Spitzer, Foundation for Sarcoidosis Research, USA

16:15-16:30 Networking and Refreshments Break @ Foyer

Workshop 2

16:30-18:00

Title: Management of hepatitis B in special situations

Ali A. Ghweil, South Valley University, Egypt

Panel Discussion

Thursday 06th December 2018 | **Day 2**

Hall

08:00-08:45

Keynote Presentation

Title: Balancing the immunity: Approach to prevent lung and retina injury in preterm infants.

Suchismita Acharya, AyuVis Research Inc, USA



08:45-09:30

Keynote Presentation

Title: Congenital diarrhea syndromes

Mohamad Miqdady, Cleveland Clinic, USA



09:30-10:00 Networking and Refreshments Break @ Foyer

Scientific Sessions: Challenges in Rare Diseases | Rare Pediatric Diseases | Future of Rare Diseases Research | Living with a Rare Diseases | Neurology Rare Diseases | Rare Diseases in Eye

Session Chair: **Jennifer Mcnary,** Rare Diseases Advocate, USA

Session Co-Chair: **Rebecca Stewart,** Rare Revolution Magazine & The Rare Youth Project, UK

10:00-10:30

Title: Bridging the information gap – Why do we need an information revolution

Rebecca Stewart, Rare Revolution Magazine & The Rare Youth Project, UK

10:30-11:00

Title: Future heredity of rare diseases and orphan drugs

Mohsen Sojoudi, Rare Diseases Foundation of Iran, Iran

Special Session: Patient Advocacy Groups

11:00-12:00

Title: The burdens of tuberous sclerosis complex for patients and caregivers

Emmanuelle Logette, Association francaise Sclerose Tubereuse de Bourneville, Switzerland

12:00-13:00

Title: Red hand challenge to raise awareness about erythromelalgia

Youmna Ghaziri, Rare Diseases Society, UAE

Lunch Break 13:00-14:00 @ Restaurant

14:00-14:30

Title: The Rare special powers: Art, science, and patient groups

Eleonora Passeri, Rare Special Powers Community, Italy

Workshop

14:30-16:00

Title: Clinical studies networks – de-risking trials and studies

Noopur Singh, Foundation for Sarcoidosis Research, USA

16:00-16:30 Networking and Refreshments Break @ Foyer

Workshop

16:30-18:00

***BEST1* mutations in young asymptomatic subjects; OCT findings**

Leyla Soraya Camarillo Blancarte, Mexican Ministry of Health, Mexico

Panel Discussion

Friday 07th December 2018 | **Day 3**

Hall

09:00- 09:45

Keynote Presentation

Title: The challenge of rare diseases in Mexico

Leyla Soraya Camarillo Blancarte, Mexican Ministry of Health, Mexico



09:45-10:30

Keynote Presentation

Title: Increasing importance of brain eating bug in Pakistan; current status and future prospects

Abdul Matin, Majmaah University, Saudi Arabia



10:30-11:00 Networking and Refreshments Break @ Foyer

Scientific Sessions: Rare Diseases | Challenges in Rare Diseases | Rare Diseases in Brain | Orphan Drug | Infectious Diseases | Rare Diseases in Eye | Treatment for Rare Diseases

Session Chair: **Suchismita Acharya,** AyuVis Research Inc, USA

Session Co-Chair: **Abdul Matin,** Majmaah University, Saudi Arabia

11:00-11:30

Title: Fetal MRI in early diagnosis in rare disease of brain

Hamid Reza Edraki, Rare Diseases Foundation of Iran, Iran

11:30-12:00

Title: Ensuring patient centricity in rare disease drug development

Jennifer Mcnary, Rare Diseases Advocate, USA

12:00-12:30

Title: The threat of zoonotic eases and ebola virus disease specifically

Stef Stienstra, Royal Dutch Navy, Netherlands

Lunch Break 12:30-13:30 @ Restaurant

Poster Presentations 13:30-14:00

Workshop

14:00-15:30

Title: Molecular diagnosis of congenital cataract using next- generation sequencing

Leyla Soraya Camarillo Blancarte, Mexican Ministry of Health, Mexico

15:30-16:00 Networking and Refreshments Break @ Foyer

Video Presentations

16:00-16:15

Title: Listening, loving and helping each other, Love your life

Debbie Hellenbrand, Patient advocate, Netherlands

16:15-16:30

Title Awaited

Rameoli, Lesotho Rare diseases Association, SA

16:30-16:45

Title Awaited

Darly Cupples, Northern Ireland

Panel Discussion

Closing Cermony