

Better Care for Rare

 **16TH September 2023** | **10:00 - 17:00**
KSA Time

 Riyadh - KSA



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AGENDA

10:00 – 11:25
85 Min

The Pursuit of Better Care for Rare

Moderator | Prof. Moeen Al Sayed & Prof. Fatma Al Jasmí

10:00 – 10:05
5 Min

Better Care for Rare Journey

Sanofi

10:05 – 10:15
10 Min

Meet our Hero

Patient testimony

10:15 – 11:15
60 Min

LSDs Prevalence & Epidemiology in our Region

Speaker | Prof. Majid Alfadhel

Upscaling the Digital Services & Screening Program

Speaker | Dr. Amal AlHashem

Psychological Support for LSD Patients

Speaker | Dr. Fathiyah Al Murshedi

Innovation in Accelerating Patients Diagnosis

Speaker | Dr. Nadia AlHashmi

Pharma Perspectives in Rare Diseases and Value Based Medicine

Speaker | Dr. Laila Abu Esba

ERT Administration Challenges & Home Care as Solutions

Speaker | MS.Wejdan Ahmed

Genetic Counseling in LSD Era

Speaker | Mr.Saud Takroni

11:15 – 11:25
10 Min

Q&A Session

Speaker | All

11:35 - 13:10
95 Min

Listen to Patient Stories. Give them Hope. Meet our Metahumans.

Moderator | Prof. Majid Alfadhel & Dr. Hind Alsharhan

11:35 – 11:55
20 Min

Hematological Manifestations in Lysosomal Storage (Meet Maryam)

Speaker | Dr. Rana Felemban

11:55 – 12:10
15 Min

Look Beyond the Obvious (Meet Aisha)

Speaker | Dr. Amal Tenejji

12:10 – 12:25
15 Min

Chase the Sign! (Meet Khalid)

Speaker | Dr. Zahra Alsahlawi

12:25 – 12:40
15 Min

Cardio Renal Manifestation (Meet Abdullah)

Speaker | Dr. Nouriya Al-Sanna'a

12:40 – 12:55
15 Min

Treatment Outcomes in LSD

Speaker | Dr. Rawda Sunbul

12:55 – 13:10
15 Min

Q&A Session

Speaker | All

14:10 – 16:00
110 Min

Reimagine the Life of ASMD Patients (Niemannpick AB & B)

14:10 – 14:15
5 Min

Introduction

Moderator | Dr. Maha Faden

14:15 – 14:35
20 Min

Burden of the Disease and Unmet Medical need in ASMD

Speaker | Dr. Tawfeg Ben-Omran

14:35 – 15:15
40 Min

Clinical Value of the Olipudase Alpha from Global Perspective

Speaker | Prof. Roberto Giugliani

15:15 – 15:30
15 Min

Local Treatment Experience with Olipudase Alpha - Case 1

Speaker | Dr. Maha Faden

15:30 – 15:40
10 Min

Local Treatment Experience with Olipudase Alpha - Case 2

Speaker | Dr. Aziza Mushibah

15:40 – 15:50
10 Min

Local Treatment Experience with Olipudase Alpha - Case 3

Speaker | Dr. Bashayer Alawam

15:50 – 16:00
10 Min

Q&A Session

Speaker | All

16:00 -16:45
45 Min

Unlocking a Treatment Choice for Patients With Late-Onset Pompe Disease

16:00 – 16:15
15 Min

Local Perspective for Redefining Pompe Disease

Moderator | Prof: Zuhair Alhassnan

16:15 – 16:35
20 Min

Global US Experience in LOPD Patient Management and with Avalglucosidase Alfa Patient Experience

Speaker | Dr. Tahseen Mozaffer

16:35 – 16:40
5 Min

Q&A Session

Speaker | Prof. Zuhair Alhassnan

16:40 – 16:45
5 Min

Meeting Closing & Remarks

Speaker | Prof. Moeen Al Sayed

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