



WORKSHOPS

Pre-Congress | Friday | September 18
Le Meridien Dubai Hotel



13:00-13:50 Registration

13:50-14:00 Welcome & Introduction

Break Out Room 1

14:00-15:00 **Workshop 1:**
Diet as Management of Rare Diseases
Instructor: Ms. Masooma Al Jasmi, UAE

Break Out Room 2

14:00-15:00 **Workshop 2:**
Genetic Counselling in Rare Diseases:
Principles and Practice
Instructor: Dr. Richa Soni, UAE

Break Out Room 1

15:00-16:00 **Workshop 3:**
Metabolic Emergency Management
Instructors: Dr. Mahra Al Fattah & Dr. Dalia Ra'a Said, UAE

Break Out Room 2

15:00-16:00 **Workshop 4:**
Genetic Testing Results: How to Interpret?
Instructor: Dr. Azza Attia, UAE

16:00-16:15 Coffee Break

Break Out Room 1

16:15-17:15 **Workshop 5:**
Approach to Bleeding Disorders
Instructor: Dr. Eman Alshamsi, UAE

Break Out Room 2

16:15-17:15 **Workshop 6:**
How to Apply for IRB / DSREC Ethics Review
for Your Clinical Research
Instructor: Dr. Badria Almurshidi, UAE

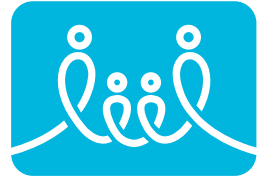
17:15 End of Workshops





FAMILY DAY AGENDA

Day 1 | Saturday | September 19
Le Meridien Dubai Hotel

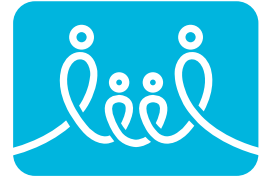


TIME	TOPICS	SPEAKER
08:00-08:50	Registration التسجيل	
08:20-08:30	Welcome & Introduction الترحيب والمقدمة	
Session 1: Premarital Genetic Screening الفحص الجيني ما قبل الزواج Chair: Dr. Fatima Abdulaziz & Dr. Mariam Alshehhi		
08:30-08:50	Inborn Error of Metabolism in Adults	Dr. Ali Al-Beshri, UAE
08:55-09:40	Pre-Marital Genetic Screening in the UAE	Dr. Suad Alawar (MOHAP) Dr. Ali Al-Beshri (SEHA) Dr. Hamdan Ahmed Ibrahim Abdullah Al Balooshi (Dubai Courts)
	His Excellency Judge	
Q & A / Panel Discussion أسئلة وأجوبة		
09:40-10:20	Official Inauguration الافتتاح الرسمي للمؤتمر وتكريم العائلات والرعاة	
10:20-10:35	Coffee Break استراحة	
FAMILY DAY (Ballroom 1) Session 2: From Hope to Impact: Initiatives that Changed the Lives of the Rare's Chair: TBA		
10:35 - 12:15	Welcome & Introduction	عن رعايتنا قايده ترويج تاريخهم بريتائنا جلالهم - انهم
Mrs. Nafisa Tawfiq – UAERDS Chairperson		
Bringing Them Out of Darkness and Into the Light: A Moroccan Experience in Protecting Children of the Moon—from Humanitarian Work to Innovation and Scientific Research An Experience in Confronting Xeroderma Pigmentosum		
Mr. Ahmed Zainoun, Winner of Hope Maker 2025 Founder and President, Son of Al Qamar Association, Morocco		
Mohammed: A Face of moonlight, a heart of patience		
Mrs. Subaha Al Shamsi, UAE		
A Nation That Empowers Its People: My Personal Journey from Inclusion to Achievement		
Shamsa AL Mehairi - Acting Head of the POD Friendly Government Entity - Government of Dubai Legal Affairs Department		
TBA		
Ms. Gabrielle Rosario, UAE		
TBA		
12:15 - 13:15	Lunch Break & Prayer	قلاصلا قدارتسا



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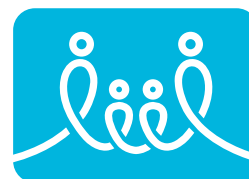


TIME	TOPICS	SPEAKER
FAMILY DAY (Ballroom 1) Session 3: POD Government Services Programs Chair: TBA		
13:15 - 14:45	POD Support programs at POD Department- Ministry of Family <i>Eman Jassim AlAli</i>	رمهلا باحصاً رمعد جمائر - قرسا قرازو - رمهلا باحصاً قراد
	POD Support Programs at Department of Social Services - Sharjah <i>Khaled Al Abdouli - Director of Wahat Al-Rushd</i>	رمهلا باحصاً رمعد جمائر - قرسا قرازو - رمهلا باحصاً قراد دشرا تاداو راد ريدم - يلو حبعلا حلاخ
	TBA	
	POD Support Programs and Child Protection <i>Ms. Fatma Al Marzouqi, UAE</i>	برامج حماية الطفل وأصحاب الهمم
	Q & A / Panel Discussion	قوجأو قلسأ
14:45 - 15:00	Coffee Break	قكارنسا
15:00 - 15:20	Industry Symposium 2 - TAIBA Healthcare (Main Hall - Ballroom 3)	Dr. Sareea Alremeithi, UAE
FAMILY DAY (Ballroom 1) Session 4: Quality of Life: Between Family Stability and Advances in Treatment Chair: Mrs. Nashemya Alfili		
15:00 - 16:50	A Panel Discussion on the Marriage of People with Disabilities: Between Reality and Challenges <i>Speakers: Dr. Nazem, Dr. Abdulla Al Hammami, Dr. Fatema AlHayyas</i> <i>Moderator: Ms. Nashmeya AlFili</i>	تايدحتلاو ققولا نيه رمهلا باحصاً جاور ناونع قيشاقت قسلا
	Treatment Approaches for Rare Diseases: Bone Marrow Therapy and Stem Cell Therapy Transplantation, Gene <i>TBA</i>	قبعجلا ايلخلا / ينجلا جلاخلا / عاخلا قعازز - قرحانلا صارم جلاخلا قيرط نيه قسلا
	Health Quality and Community Prosperity <i>H.E. Dr. Eman AlHashmi, UAE</i>	جودة الصحة وازدهار المجتمع
	TBA	
	Q & A / Panel Discussion	قوجأو قلسأ
16:50 - 17:00	Sponsors Awarding and Closing & End of Day	



CONGRESS AGENDA

Day 1 | Saturday | September 19
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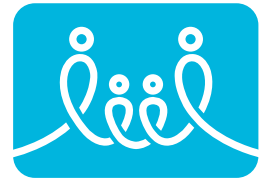
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	His Excellency Judge	Dr. Ali Al-Beshri (SEHA)
		Dr. Hamdan Ahmed Ibrahim Abdullah
		Al Balooshi (Dubai Courts)
	Q & A / Panel Discussion أسئلة وأجوبة	
09:40-10:20	Official Inauguration الافتتاح الرسمي للمؤتمر وتكريم العائلات والرعاة	
10:20-10:35	Coffee Break استراحة	
MAIN HALL (Ballroom 3) Session 2: Innovation in Rare Disease Chair: Dr. Amal Al Tenaiji & Dr. Noor Almeheri		
10:35 - 10:55	Newborn Screening by Next Generation Sequencing, Challenges, & Benefits	Dr. Hamda Abulhoul, UAE
10:55 - 11:15	Novel Diagnostic / Laboratory Methods	Dr. Osama Aldirbashi, Qatar
11:15 - 11:35	Novel Therapeutic Approach to Metabolic Genetic Disorders	Dr. Amal Mohammed Alhashem, UAE
11:35 - 12:05	Symposium (Sanofi) - Neurological Manifestation of GD3	Dr. Amal Alteneiji, UAE
12:05 - 12:15	Q & A / Panel Discussion	
12:15 - 13:15	Lunch Break & Prayer فلتا ولا صلاة	
MAIN HALL (Ballroom 3) Session 3: Metabolism and Biochemical Genetics Chair: Dr. Amel Aljasmi Almaeeni & Dr. Noura Aldhaheer		
13:15 - 13:35	New and rare Inherited bone marrow failure syndromes	Dr. Leslie Lehmann, USA
13:35 - 13:55	Updates on Phenylketonuria	Dr. Amal Al Tenaiji, UAE
13:55 - 14:15	Insights on Lysosomal Storage Disease	Prof. Fatma Aljasmi, UAE
14:15 - 14:35	Updates in MPS II Management	Dr. Hind Alsharhan, Kuwait
14:35 - 14:45	Q & A / Panel Discussion مقابلات وأجوبة	
14:45 - 15:00	Coffee Break قهوة	
15:00 - 15:20	Industry Symposium 2 - TAIBA Healthcare (Main Hall - Ballroom 3)	Dr. Sareea Alremeithi, UAE



4TH INTERNATIONAL UAE
RARE DISEASE SOCIETY CONGRESS
United for Rare: Empowering Families, Advancing Care

CONGRESS AGENDA

Day 1 | Saturday | September 19
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TIME	TOPICS	SPEAKER
MAIN HALL (Ballroom 3) Session 4: TBA Chair: Dr. Faizah Hashimy & Dr. Halima Aldhanhani		
15:20 - 15:40	TBC	Dr. Anne Slavotinek, USA
15:40 - 16:00	TBC	Dr. Benjamin Cocanougher, USA
16:00 - 16:20	Autism, Insight about Genetics	Dr. Maryam Alshehhi, UAE
16:20 - 16:40	Decoding PACS1 Syndrome: From Gene Discovery to Precision Therapy	Dr. Gary Thomas, USA
16:40 - 16:50	Q & A / Panel Discussion سؤال وجواب	
16:50 - 17:00	Sponsors Awarding and Closing & End of Day	





CONGRESS AGENDA

Day 2 | Sunday | September 20
Le Meridien Dubai Hotel



TIME	TOPICS	SPEAKER
08:00-08:50	Registration	
08:50 - 09:00	Welcome & Introduction	
Session 5: Metabolic Emergencies Session Chair: Dr. Mahra Alfattan & Dr. Ali Al-Beshri		
09:00 - 09:20	Porphyria, Insights on New Treatment	Dr. Nadia Alhashmi, Oman
09:20 - 09:40	Insights on Urea Cycle Defects	Dr. Noura Aldhaheri, UAE
09:40 - 10:10	Genetics Role in Intensive Care Management	Dr. Ahmad Abou Tayoun, UAE
10:00 - 13:00	PTC Workshop (Breakout Room)	Ms. Fatemah Alawadhi, Kuwait
10:10 - 10:30	Industry Symposium 3 – GenPharm (20 mins)	Dr. Amal Altenaiji, UAE
10:30 - 10:40	Q & A / Panel Discussion	
10:40 - 10:55	Coffee Break	
Session 6: Treatable Metabolic Disorders Chair: Dr. Dalia Alraei Said & Dr. Heba Elabd		
10:55 - 11:15	Vitamin Responsive Disorders	Dr. Tawfeg Ben Omran, Qatar
11:15 - 11:35	CTX, Rare Cause of Adult Neurological Disease	Dr. Arif Khan, UAE
11:35 - 11:55	Ataxia, Treatable Causes	Dr. Aman Sohal, UAE
11:55 - 12:15	From Genetics to Hemodynamics: Hereditary Pediatric Pulmonary Hypertension from Genetic Perspective	Dr. Ahmed Adel, UAE
12:15 - 12:35	Industry Symposium 4 - Biologics (20 mins)	
12:35 - 12:45	Q & A / Panel Discussion	
12:45 - 13:45	Lunch Break & Prayer	
Session 7: Genetics Chair: Dr. Waed Sumairi & Dr. Sara Alsuwaidi		
13:45 - 14:05	The Role of Family Physician in Genetic Era	Dr. Aisha Abdullah, UAE
14:05 - 14:25	Obesity, Genetic Perspective	Dr. Asma Deeb, UAE
14:25 - 14:45	Skeletal Dysplasias and Growth Hormone	Dr. Zulf Mughal, UAE
14:45 - 15:05	Pneumonia; When to Think about Genetics?	Dr. Moeen Alsayed, KSA
15:05 - 15:25	Industry Symposium 5 - Immedica (20 mins)	TBC
15:25 - 15:35	Q&A / Panel Discussion	
15:35 - 15:45	Coffee Break	
Session 8: Ethics & Research Chair: Dr. Fatma Aljasmi & Dr. Eman Taryam Alshamsi		
15:45 - 16:05	Ethics meets Genetics	Dr. Moeen Alsayed, KSA
16:05 - 16:25	What's next: Genetic Testings are Negatives	Dr. Hiba Alblooshi, UAE
16:25 - 16:45	Interpretation of Genetic Results, Cases	Dr. Heba Elabd, UAE
16:25 - 16:45	Q & A / Panel Discussion	
16:55	End of Congress	



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SPONSORED WORKSHOPS

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Break Out Room 1

10:15-12:15



Workshop 7 By PTC:
Navigating PKU: From Challenges to Confidence
Instructor: Ms.Fatemah Al Awadhi

