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دائرة الشؤون القانونية
THE GOVERNMENT OF DUBAI LEGAL AFFAIRS DEPARTMENT

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DUBAI
Business Events



4TH INTERNATIONAL UAE RARE DISEASE SOCIETY CONGRESS

United for Rare: Empowering Families, Advancing Care

PRE-CONGRESS WORKSHOPS

18 SEPT 2026

CONGRESS

19-20 SEPT 2026



Le Meridien Dubai Hotel, UAE



Academic Partner

Endorsed by

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UAUU جامعة الإمارات العربية المتحدة
College of Medicine and Health Sciences United Arab Emirates University

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EHS
مؤسسة الإمارات للخدمات الصحية
Emirates Health Services

AUTOI AIA UNE ASSOCIATION
جمعية المناعة الذاتية





WELCOME MESSAGE

Dear Colleagues,

On behalf of the Scientific and Organizing Committees, as well as the UAE Rare Disease Society, it is my great pleasure to welcome you to attend the **4th UAE Rare Disease Society Congress 2026**, taking place **18-20 September 2026** at Le Meridien, Dubai. The event will open with pre-congress workshops on 18 September, followed by the main congress sessions on 19 and 20 September 2026.

This year's congress is held under the theme: **United for Rare: Empowering Families, Advancing Care**, reflecting our collective commitment to strengthening support systems, advancing scientific knowledge, and improving patient outcomes.

As President of this year's congress, I am deeply honored to host this gathering of distinguished experts, researchers, advocates, and individuals committed to improving the lives of those affected by rare diseases. This congress provides a vital platform for sharing groundbreaking research, fostering collaboration, and advancing progress in the diagnosis, treatment, and support of patients with rare diseases. Our collective efforts are essential in addressing the unique challenges faced by this community, and I am confident that the knowledge, partnerships, and insights gained here will leave a lasting impact.

Although rare diseases are individually uncommon, together they affect millions worldwide, presenting both complex challenges and remarkable opportunities. Research into these conditions often reveals fundamental biological mechanisms, offering insights into more prevalent diseases and driving innovation in diagnostics, therapeutics, and personalized medicine. This focus not only benefits individuals living with rare diseases but also enriches the broader medical field, pushing the boundaries of science and patient care.

I warmly encourage each of you to participate actively, engage in meaningful discussions, and share your expertise. By working together, we can amplify the voices of those living with rare conditions and move closer to a brighter, more equitable future for all.

Dr. Nuha Alzaabi

Congress President
Metabolic Genetic Consultant
UAE Rare Disease Society





SCIENTIFIC COMMITTEE



Dr. Nuha Alzaabi
Congress President
Metabolic Genetic Consultant
UAE Rare Disease Society



Prof. Fatma Al Jasmi
MBBS, FRCPC, FCCMG
Dean of CMHS, UAEU
Biochemical Genetics Consultant,
Tawam Hospital



Dr. Fatma Al Bastaki
BSc, MBBS, DCH, MSc, FRCPC
Consultant Clinical Geneticist -
HMS Mirdif Hospital



Dr. Amal AL Tenaiji
Consultant Clinical Geneticist,
Sheikh Khalifa Medical City



Dr. Eman Taryam AlShamsi
MBBS, RCPCH
Consultant Pediatric
Hematologist Oncologist,
Dubai, UAE



Dr. Mohamed Naveed
Consultant Geneticist
Department of Pediatrics,
Fujairah Hospital,
Emirates Health Services (EHS), UAE



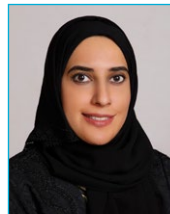
Dr. Badria Almurshidi
Specialist
Dubai Health Authority (DHA),
Dubai, UAE



Prof. Bassam Ali
Professor of Genetics and
Genomic Medicine
College of Medicine and
Health Sciences, UAE University,
Al Ain, Abu Dhabi



Prof. Shreesh Ojha
Professor of Pharmacology &
Therapeutics
College of Medicine &
Health Sciences, UAE University,
Al Ain, Abu Dhabi



Dr. Hamda Hassan Khansaheb
Director of Research Administration
and Support; Associate Professor
of Family Medicine
Mohammed Bin Rashid University
of Medicine and Health Sciences
(MBRU), Dubai Health





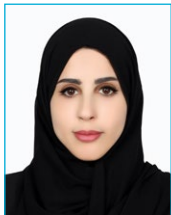
ORGANIZING COMMITTEE



Mrs. Nafisa Tawfiq
Chair President
UAE Rare Disease Society




Mrs. Awatif Aljasmi
Head of Administrative Services
Dubai Health Authority's
Thalassemia Center

Ms. Dalal Al Dhabyani
Director of Operation
UAE Rare Disease Society




Ms. Aadla Jodat
Executive Administrative
UAE Rare Disease Society




Dr. Azhar Rahma
Instructor at the Institute of
Public Health,
College of Medicine and
Health Sciences, UAE




Dr. Fatima AbdulAziz
Consultant Pediatric-Clinical
Genetics and Genomics




Dr. Madiha Fathi Ibrahim
Consultant Pediatrician
Al Qassimi Women & Children Hospital
AQWCH, Assistant Professor
Sharjah University, UAE




Mrs. Zalaikha Alhammadi
Senior Specialist - Metabolic Genetic Unit
Dubai Genetic Centre






CONFERENCE OBJECTIVES

- To enhance awareness and understanding of rare diseases among healthcare professionals and the general public.
- To provide a platform for sharing the latest research, diagnostic, and therapeutic advancements in rare diseases.
- To facilitate networking and collaboration among stakeholders in the rare disease community.
- To promote patient advocacy and support for individuals and families affected by rare diseases.
- To discuss challenges and opportunities in rare disease diagnosis, treatment, and access to care in the UAE and the region.
- To educate healthcare providers on the importance of early diagnosis and appropriate management of rare diseases.
- To improve the quality of life for patients and families affected by rare diseases.

WHY ATTEND THE CONGRESS (KEY POINTS)

- Gain insights into the latest advancements in rare disease research and treatment.
- Network with leading experts, researchers, and clinicians in the field.
- Learn about best practices in diagnosis, management, and care of rare disease patients.
- Connect with patient advocacy groups and families affected by rare diseases.
- Earn continuing medical education (CME) credits.
- Contribute to the growing awareness and understanding of rare diseases in the UAE & the region.
- Discover new opportunities for collaboration and research.
- Stay updated on the latest policies and initiatives related to rare diseases.
- Be part of a community dedicated to improving the lives of those affected by rare diseases.

CME ACCREDITATION

The 4th UAE Rare Disease Society Congress 2026 has been accredited by the European Accreditation Council for Continuing Medical Education (EACCME®) and is designated for a maximum of **15 European CME credits (ECMEC®s)**.

DAY 1, Friday 18/09/2026 is Accredited for 3.0 CME Hours

DAY 2, Saturday 19/09/2026 is Accredited for 5.5 CME Hours

DAY 3, Sunday 20/09/2026 is Accredited for 6.5 CME Hours





TARGET AUDIENCE

- Geneticists
- General Pediatricians
- Pediatric sub-specialty
- Cardiologists
- Pulmonologists
- Endocrinologists
- Neonatologists
- Oncologists
- Hematologists
- Ophthalmologists
- ENT
- Dermatologists
- Neurologists
- Nephrologists
- Rheumatologists
- Anesthesiologists
- ENT specialist
- Family physicians
- Internalist
- Metabolic Consultants
- Psychiatrists
- Genetic Counselors
- Nurses
- Dieticians
- Metabolic Dieticians
- Physiotherapists
- Learning difficulties specialists
- Speech Therapists
- Academic scientists
- Researchers
- Medical / Science students
- Laboratory technologist - Genetics
- Molecular geneticist
- Cytogenetic specialist
- Trainers
- Rare Heroes / Rare Families / Rare Caregivers.
- Community service providers
- POD service providers
- Non-Profit Organizations.
- Patients Advocacy Bodies.
- POD/Special Needs Business-Application Developers.

CONGRESS HIGHLIGHTS

- Genetics and Genomics of Rare Diseases
- Newborn Screening for Rare Disorders
- Diagnostic Approaches and Challenges
- Innovative Therapies and Clinical Trials
- Patient Advocacy and Support
- Ethical Considerations in Rare Disease Management
- Rare Disease Registries and Data Collection
- Specific Rare Disease Focus (e.g., metabolic disorders, neurological disorders, etc.)
- The role of Artificial Intelligence in Rare Diseases





WORKSHOP SPEAKERS



Ms. Masooma Al Jasmi

Head of Clinical Nutrition
Al Jalila Children's Specialty Hospital,
Dubai, UAE



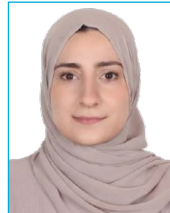
Dr. Richa Soni

Physician Clinical Geneticist
Al Qassimi Women's and Children's Hospital
Emirates Health Services (EHS), Sharjah,



Dr. Mahra Al Fattan

Fellow/ Specialist
SEHA, Tawam Hospital,
Al Ain, Abu Dhabi, UAE



Dr. Dalia Ra'a Said

Clinical Genetics Fellow
Tawam Hospital, Al Ain,
Abu Dhabi, UAE



Dr. Eman Taryam AlShamsi

MBBS, RCPCH
Consultant Pediatric
Hematologist Oncologist,
Dubai, UAE



Dr. Azza Attia

Clinical geneticist,
Head of Clinical Genomics
G42, Abu Dhabi, UAE



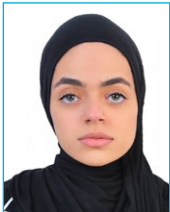
Dr. Badria Almurshidi

Specialist
Dubai Health Authority (DHA),
Dubai, UAE



Ms. Fatemah Al Awadhi

PICU, NICU & Inborn Errors of
Metabolism Dietitian,
Farwaniya Hospital, Kuwait



Ms. Zahra Abdulaal

HPP, Bahrain



Dr. Zahra Alsahlawi

Consultant inborn error of metabolism
and Clinical genetics - Assistant Professor
Government hospitals,
Arabian Gulf University



Dr. Ahlam Al Marzooqi

Consultant Rheumatologist &
Internal Medicine Consultant
Al Qassimi Hospital,
Emirates Health Services (EHS), Sharjah, UAE



Ms. Zainab Abdulaal

Bahrain



Mrs. Khadija Ismaeel

Bahrain



Dr. Shaden Abdelhadi

Consultant Pediatric Dermatology
Adjunct Professor of Dermatology,
Khalifa University
Sheikh Khalifa Medical City,
Abu Dhabi, UAE





WORKSHOP SPEAKERS



Ms. Chaza Alaa Eddin
Registered Nurse
Sheikh Khalifa Medical City,
Abu Dhabi, UAE




Mr. Imti Rafiq
IT professional, Qatar




Ms. Salama Ali Al Nuaimi
Advocate living with EBS




Ms. Abrar Al-Othman
UAE




Ms. Abrar Al Othman
Media Personality & Influencer; Author
& Epidermolysis Bullosa (EB) Advocate,
Saudi Arabia

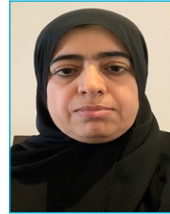





SPEAKERS



Dr. Ali Al-Beshri
Consultant Clinical
Genetics & Genomics
Tawam Hospital, Al Ain,
Abu Dhabi, UAE



Dr. Suad Alawar
Head of Family Health Section/
Public Health Expert/
Consultant Family Physician
Ministry of Health and Prevention
(MOHAP), UAE



Dr. Ali Elthabahi
Judge and Head of the Personal
Status Appeals Circuit
Dubai Courts, UAE



Mrs. Nafisa Tawfiq
Chair President
UAE Rare Disease Society,
UAE



Dr. Hamda Abulhoul
Consultant, Pediatric
Inherited Metabolic Medicine
Al Jalila Children's Hospital,
Dubai, UAE



Dr. Osama Aldirbashi
Senior Consultant Clinical Scientist
Metabolic Lab, Department of
Laboratory Medicine and Pathology
Hamad Medical Corporation, Qatar



Dr. Amal Mohammed Alhashem
Consultant/ Professor/
Chairperson Genetic Department
King Fahad Specialist Hospital-
Alfaisal University, Saudi Arabia



Dr. Amal AL Tenaiji
Consultant Clinical Geneticist,
Sheikh Khalifa Medical City



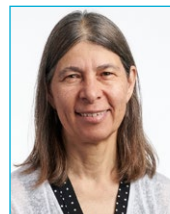
Dr. Leslie Lehmann
Director, Clinical Stem Cell
Transplantation Program
Medical Director, International
Hematology/Oncology/BMT
Associate Professor,
Harvard Medical School



Dr. Encarna Guillen
Head of Genomic Medicine
UNICAS Strategic Director
Sant Joan de Déu Barcelona
Children's Hospital, Spain



Dr. Fatima Nuñez
Research Deputy Director
Sant Joan de Déu Barcelona
Children's Hospital, Spain



Dr. Anne Slavotinek
Director, Division of Human Genetics
Professor, UC Department of Pediatrics
Cincinnati Children's Hospital, USA





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

SPEAKERS



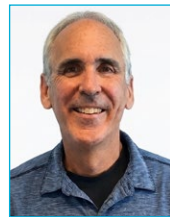
Prof. Fatma Al Jasmi
MBBS, FRCPC, FCCMG
Dean of CMHS, UAEU
Biochemical Genetics Consultant,
Tawam Hospital



Dr. Sareea Al Remeithi
Consultant Pediatric Endocrinology
Sheikh Khalifa Medical City,
Abu Dhabi, UAE



Dr. Hind Alsharhan
Assistant Professor of Pediatrics,
Medical and Biochemical Geneticist
Department of Pediatrics Kuwait University,
Faculty of Medicine, Kuwait



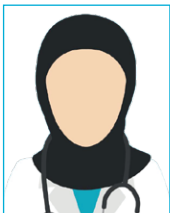
Dr. Gary Thomas
PhD, Center for Rare Disease Therapy
University of Pittsburgh School of Medicine
Pittsburgh, PA, USA



**Dr. Maryam Mohammed
AL Shehhi**
Consultant - Pediatrics Clinical Genetics
Sheikh Khalifa Medical City,
Abu Dhabi, UAE



Dr. Nadia Alhashmi
Head of Training Section at NGC,
Sr. Consultant (Medical Genetic)
Royal Hospital, Oman



Dr. Fatima Rabea
PhD, Mohammed Bin Rashid University
of Medicine and Health Sciences (MBRU)
Dubai Health, UAE



Dr. Noura Aldhaheeri
Assistant Professor and Consultant,
Clinical Genetics & Metabolism
College of Medicine & Health Sciences,
UAE University



Dr. Tawfeg Ben Omran
Division Chief, Genetic and
Genomic Medicine - Sidra
Senior Consultant,
Department of Medical Genetics - HMC
Professor, Weill Cornell Medical College
Professor, College of Health Services,
Qatar University



Dr. Arif Khan
Section Head, Pediatric &
Neuro Ophthalmology
Cleveland Clinic Abu Dhabi, UAE



Dr. Theodore W. Laetsch
Attending physician, Cancer Center
Children's Hospital of Philadelphia
(CHOP), USA

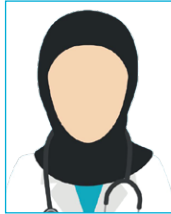


Dr. Ahmed Adel Hassan
Consultant Pediatric Cardiologist
Al Jalila Children's Heart Center,
Dubai, UAE





SPEAKERS



Dr. Aisha Abdullah

Director of Primary Health Care Fujairah
Consultant Family Physician,
EHS, UAE



Dr. Asma Deeb

Chair of Paediatric
Endocrinology Division
Sheikh Shakhbout Medical City,
Abu Dhabi, UAE



Dr. Zulf Mughal

Consultant,
Paediatric Bone Disorders
Al Jalila Children's Hospital,
Dubai, UAE



Dr. Benjamin Cocanougher

Medical Geneticist, Division of Human
Genetics, Physician-Scientist,
Division of Human Genetics
Assistant Professor,
UC Department of Pediatrics
Cincinnati Children's Hospital, USA



Dr. Moeen AlSayed, MD, FACMG, MBA
Professor of Genetics, College of Medicine,
Alfaisal University; Director, MSc Genetic
Counselling Program, Alfaisal University
Consultant, Department of Medical Genomics,
Center for Genomic Medicine; King Faisal
Specialist Hospital & Research Center, KSA



Dr. Hiba Alblooshi

Assistant Professor /
Director of UAEU Genomics laboratory
UAE University, Al Ain, Abu Dhabi, UAE



Dr. Heba Elabd

Medical Genetic Consultant
Al Jalila Children's Hospital,
Dubai, UAE



Dr. Mehtab Iqbal

Consultant Pediatric Neurologist
Tawam Hospital, Al Ain, UAE



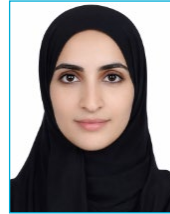


FAMILY DAY SPEAKERS



Mr. Ahmed Zainoun

Founder and President
Son of Al Qamar Association,
Morocco
Winner of Hope Maker 2025



Mrs. Sabha Al Shamsi

Zayed Higher Organization
for People of Determination,
UAE



Ms. Shamsa Almheiri

Acting Head of the POD Friendly
Government Entity - Government
of Dubai Legal Affairs Department



Ms. Eiman Jassim Al Ali

Specialist
People of Determination Support Programs
at the UAE Ministry of Family



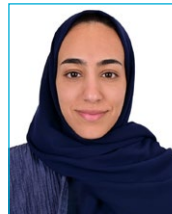
Mr. Khaled Al Abdouli

Director - Wahat Al-Rushd
Sharjah, UAE



Ms. Fatma Al Marzouqi

UAE Ministry of Family



Ms. Nehad Al Hemeiri

POD Department
Community Development
Authority Dubai, UAE



Mr. Rashed Bin Haider

Child Protection Department
Community Development Authority,
Dubai, UAE



Mr. Nazem Almanssour

People of Determination and
Senior Citizens Empowerment
Assistant Expert



Dr. Abdulla Al Hammami

Assistant Specialist - Visual Impairment;
Family and Educational Consultant
Emirates Schools Establishment (ESE), UAE



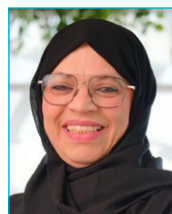
Dr. Fatema AlHayyas

Specialist Psychiatrist
Sheikh Khalifa Medical City (SKMC),
Abu Dhabi, UAE



H.E. Dr. Eman AlHashmi

Founder and Chairperson
Autoimmune Association, UAE



Ms. Fida Diyab

Mother of rare hero and founder
and POD monitoring smart watch - TAPY





MODERATORS



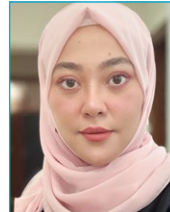
Dr. Fatima AbdulAziz
Consultant Pediatric-Clinical
Genetics and Genomics



Dr. Noor Almeheri
Director, Mental Health Department
and Visiting Consultant Programme
Emirates Health Services, UAE



Dr. Amel Aljasmi Almaeeni
Assistant Director for Medical Affairs
Consultant OB/GYN,
HOD of OBGYN Department
Fujairah Hospital, UAE



Dr. Faizah Hashimy
Specialist Physician – General Pediatrics,
with a clinical focus on metabolic disorders
Sheikh Khalifa Medical City,
Abu Dhabi - SEHA



Dr. Halima Aldhanhani
Head of Pharmacy
Fujairah Hospital –
Emirates Health Services



Dr. Waed Sumairi
Clinical Genetics Fellow
Tawam hospital,
Al Ain, Abu Dhabi, UAE



Dr. Sara Alsuwaidi
Consultant Family Physician and
Head of Policies and Standards,
Hospitals Department
Emirates Health Services, UAE



Mrs. Nashemya Alfili
UAE Rare Disease





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
08:55-09:40	جلسة حوارية مشتركة عن الفحص الجيني ما قبل الزواج في دولة الامارات العربية المتحدة Premarital Genetic Screening in the UAE	د. علي البشري د. سعاد العوز - وزارة الصحة ووقاية المجتمع د. سعادة القاضي / د. علي الخياحي - قاضي تمييز اول - محاكم دبي Dr. Suad Alawar (MOHAP), Dr. Ali Al-Beshri (SEHA) Dr. Ali Elthabahi (Dubai Courts)
Q & A / Panel Discussion أسئلة وأجوبة		
09:40-10:20	Official Inauguration الافتتاح الرسمي للمؤتمر وتكريم العائلات والبراعة	
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

من الأمل إلى التأثير: مبادرات غيرت حياة النادرين

10:35-10:45 10 mins	كلمة الترحيب لبرنامج العائلة Welcome & Introduction	Mrs. Nafisa Tawfiq - UAERDS Chairperson
10:45-11:05	جمعية أطفال القمر بالمغرب Association moon voice - Morocco	لسيد أحمد زينون - الفائز بجائزة صناع الأمل ٢٠٢٥ Mr. Ahmed Zainoun - winner of hope maker 2025
11:05-11:15	محمد وجه من نور القمر وقلب من الصبر Muhammad: A Face of Moonlight, a Heart of Patience	لسيدة / صبحه الشامسي Mrs. Subha AlShamsi
11:15-11:35 10 mins	وطن يمكن أبناءه: رحلتي الشخصية من الدمج إلى الإنجاز A Nation That Empowers Its People: My Personal Journey from Inclusion to Achievement	شمسة المهيري - نائب رئيس فريق الجهة الحكومية الصديقة لأصحاب الهمم - دائرة الشؤون القانونية لحكومة دبي Shamsa AL Mehairi - Acting Head of the POD Friendly Government Entity - Government of Dubai Legal Affairs Department
11:35-11:55	TBA	Ms. Gabrielle Rosario, UAE
11:55-12:15 Q & A		
12:15-13:15 Lunch Break & Prayer استراحة الصلاة		



FAMILY DAY AGENDA

Day 1 | Saturday | September 19
Le Meridien Dubai Hotel



TIME	TOPICS	SPEAKER
FAMILY DAY (Ballroom 1) Session 3: POD Government Services Programs برامج الخدمات الحكومية لأصحاب الهمم Chair: Dr. Madiha Fathi Ibrahim, Ms. Dalal Al Dhabyani		
13:15-13:35 20 mins	إدارة أصحاب الهمم - وزارة الأسرة - برامج دعم أصحاب الهمم POD Support programs at POD Department- Ministry of Family	إيمان جاسم آل علي - أخصائي أول تشخيص وتقييم - وزارة الأسرة Eiman Jassem Al Ali Inspection Services Senior Specialist - Ministry of Family
13:35-13:55 20 mins	دائرة الخدمات الاجتماعية بإمارة الشارقة - برامج دعم أصحاب الهمم POD Support programs at Department of Social Services - Sharjah	خالد العبدولي - مدير دار واحات الرشيد Khaled Al Abdouli - Director of Wahat Al-Rushd
13:55-14:25 30 mins	برامج حماية الطفل وأصحاب الهمم POD Support programs and child protection	د. فاطمة المرزوقي مدير مركز حماية الطفل والأسرة - دائرة الخدمات الاجتماعية بالشارقة - الاختصاصية/ نهاده الحميري إدارة أصحاب الهمم - هيئة تنمية المجتمع - دبي الاختصاصي / راشد دين حيدر إدارة الطفل - هيئة تنمية المجتمع - دبي Dr. Fatima Al Marzouqi Director of the Family and Child Protection Centre - Sharjah Social Services Department (SSSD) Nehad Al Hemeiri POD Department - Community Development Authority -Dubai Rashed Bin Haider Child Protection Department - Community Development Authority -Dubai
14:25 - 14:35	Q & A / Panel Discussion أسئلة وأجوبة	
14:35 - 14:50	Coffee Break استراحة	
FAMILY DAY (Ballroom 1) Session 4: Quality of Life: Between Family Stability and Advances in Treatment جودة الحياة بين الاستقرار الأسري وتطور العلاجات Chair: Mrs. Nashmeya AlFili		
14:50-15:10	جودة الصحة وإزدهار المجتمع Health Quality and community prosperity	سعادة / د. إيمان الهاشمي مؤسس ورئيس مجلس إدارة جمعية المناعة الذاتية - الإمارات H.E. Dr. Eman Al-Hashmi founder and president of Autoimmune Association - UAE
15:10-15:30	المحنة التي صنعت الأمان... قصة ابتكار ساعة تابي أمان From Adversity to Safety... The Inspiring Story of the Tapi Aman Smart Watch	د. فداء دياب Dr. Feda Diyab
15:30-16:45	جلسة نقاشية بعنوان زواج أصحاب الهمم بين الواقع والتحديات A panel discussion on the marriage of people with disabilities:	أ/ ناظم المنصور - وزارة الأسرة د. عبد الله الهمامي د. فاطمة الهياس Mr. Nazem Al Manssour - Ministry of Family Dr. Abdulla Al Hammami Dr. Fatema Al Hayyas
16:45 - 17:00	Q & A / Panel Discussion أسئلة وأجوبة	
17:00	Sponsors Awarding & CLOSING & END OF DAY تكريم الرعاية - ختام برنامج يوم العائلة	



FAMILY DAY WORKSHOPS

Sunday | September 20
Le Meridien Dubai Hotel



Al Wasl 6

10:15-12:15

Family Workshop 1 By PTC:

Navigating PKU: From Challenges to Confidence
Instructor: Ms. Fatemah Al Awadhi



رحلة التعامل مع مرض بيلة الفينيل كيتون (PKU): من التحديات إلى الثقة
المدرسة: الأستاذة فاطمة العوضي

Al Wasl 5

13:45-15:45

Family Workshop 2 By GenPharm:

Awareness Workshop on Epidermolysis Bullosa (EB)
Instructors: Dr. Shaden Abdelhadi, Ms. Abrar Al Othman
Ms. Chaza Alaa eddin



ورشة توعوية حول مرض انحلال البشرة الفقاعي (EB):
المدرسون: د. شادن عبد الهادي،
الأستاذة هيفاء، الأستاذة إمتي رفيق

Awareness Workshop on Epidermolysis Bullosa (EB) - Duration: 2 hours (2:30 – 4:30 PM – 20/09/2026)

Welcome & Overview of the workshop objectives, agenda, and expected outcome and Establishing a Family Support Group announcement

Presenter: Mrs. Nafisa Tawfiq

Introduction to the family support group and discussion of opportunities for connection, mutual support, and shared resources. Overview of the workshop objectives, agenda, and expected outcome.

الترحيب والإعلان عن تأسيس مجموعة دعم للأسر، واستعراض أهداف الورشة
المقدمة: السيدة نفيسة توفيق
التعريف بمجموعة دعم الأسر ومناقشة فرص التواصل والدعم المتبادل وتبادل الموارد، إلى جانب استعراض أهداف الورشة ومحاورها والنتائج المتوقعة

Understanding Epidermolysis Bullosa (EB)

Presenter: Dr. Shaden Abdulhadi

An overview of Epidermolysis Bullosa (EB), including its main types, symptoms, complications, treatment and management, and its impact on daily life across different stages of life.

التعريف بمرض انحلال البشرة الفقاعي (EB)

المقدمة: د. شادن عبد الهادي

التعريف بمرض انحلال البشرة الفقاعي، بما في ذلك أنواعه الرئيسية وأعراضه ومضاعفاته وعلاجه وتأثيره في الحياة اليومية بمراحله العمرية

Wound Care and Infection Prevention

Presenter: Chaza Alaa Eddin

Practical guidance on wound care, dressing techniques, pain management, and infection prevention.

العناية بالجروح والوقاية من العدوى

المقدمة: الممرضة شذى علاء الدين

إرشادات عملية حول العناية بالجروح، وطرق تغيير الضمادات، والسيطرة على الألم، والوقاية من العدوى

The EB Youth Community (20 mins)

Presenter: Mr. Imti Rafiq

Exploring youth engagement, peer support, leadership, and opportunities for community building.

مجتمع الشباب المصابين بانحلال البشرة الفقاعي (٢٠ دقيقة)

المقدمة: السيد إمتي رفيق

استكشاف سبل مشاركة الشباب، ودعم الأقران، وتنمية المهارات القيادية، والفرص المتاحة لبناء مجتمع داعم

Living with EB in Adulthood

Presenter: Ms. Salama Alnuaimi – Ms. Abrar Alotman

Discussion of adult experiences, independence, employment, relationships, and common challenges in adulthood.

الحياة مع انحلال البشرة الفقاعي

المقدمة: الاستاذة / سلامة النعيمي – السيدة / أبرار العثمان

مناقشة تجارب البالغين، والاستقلالية، والعمل، والعلاقات، والتحديات الشائعة خلال مرحلة البلوغ

Experience Sharing and Group Discussion

Facilitator: Workshop Team

A structured opportunity for participants to share experiences, discuss challenges, and exchange practical insights.

مشاركة التجارب والنقاش الجماعي

المشاركين: فريق الورشة

إتاحة مساحة منظّمة للمشاركين لمشاركة تجاربهم، ومناقشة التحديات، وتبادل الخبرات والحلول العملية

الفراسات الوردية: جلسة نقاش خاصة

المشاركين: فريق الورشة

جلسة سرية لمناقشة التحديات الجسدية والنفسية والاجتماعية الخاصة التي تواجهها النساء والفتيات المصابات بانحلال البشرة الفقاعي

Al Wasl 4

11:00-13:00

Family Workshop 3 By AstraZeneca:

HPP Disease Connect Workshop Understanding, Connecting, Supporting & Empowering the HPP Community

Moderator: Dr. Amal Altenaiji, UAE

Speakers: Dr. Zahra Alsahlawi, Bahrain, Bahrain - Dr. Ahlam Al Marzooqi, Bahrain - Dr. Amal Alteneiji, UAE - Dr. Maryam Alshehhi, UAE
Ms. Zahra Abdulaal, Bahrain



تواصل HPP



CONGRESS AGENDA

Day 1 | Saturday | September 19
Le Meridien Dubai Hotel



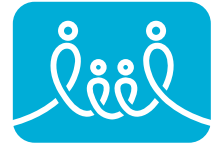
TIME	TOPICS	SPEAKER
08:00-08:50	Registration التسجيل	
08:20-08:30	Welcome & Introduction الترحيب والمقدمة	
Session 1: Premarital Genetic Screening الفحص الجيني ما قبل الزواج Chair: Dr. Fatima Abdulaziz & Dr. Mariam Alshehhi		
08:30-08:50	Inborn Error of Metabolism in Adults	Dr. Ali Al-Beshri, UAE
08:55-09:40	Pre-Marital Genetic Screening in the UAE	Dr. Suad Alawar (MOHAP)
	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	Beyond the Hospital: Taking Rare Disease Care Home	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 1 Sanofi Beyond the Spleen: The Neurological Face of Gaucher Disease	Dr. Amal Alteneiji, UAE
12:05 - 12:15 Q & A / Panel Discussion قلاصلا ةكابرئسا		
12:15 - 13:15 Lunch Break & Prayer		
MAIN HALL (Ballroom 3) Session 3: Metabolism and Biochemical Genetics Chair: Dr. Amel Aljasmi Almaeeni & Dr. Noura Aldhaheiri		
13:15 - 13:35	New and rare Inherited bone marrow failure syndromes	Dr. Leslie Lehmann, USA
13:35 - 13:55	UNICAS: Sant Joan de Deu Hospital's Innovative Strategy to Address Rare Diseases	Dr. Encarna Guillen, Spain
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 قباوؤو ةلئسا		
14:45 - 15:00 Coffee Break قلاصلا ةكابرئسا		
15:00 - 15:20	Symposium 2 GenPharm - FAODs: When Fat Can't Fuel	Dr. Amal Altenaiji, UAE



4TH INTERNATIONAL UAE
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CONGRESS AGENDA

Day 1 | Saturday | September 19
Le Meridien Dubai Hotel



TIME	TOPICS	SPEAKER
MAIN HALL (Ballroom 3) Session 4: Genomic Insights and Emerging Precision Therapies Chair: Dr. Faizah Hashimy & Dr. Halima Aldhanhani		
15:20 - 15:40	NFIX missense variants that disrupt the β -hairpin loop result in a severe form of Malan syndrome in adolescence with rapidly evolving scoliosis and muscle wasting	Dr. Benjamin Cocanougher, USA
15:40 - 16:00	Advanced Therapies Program of Sant Joan de Deu hospital	Dr. Fatima Nuñez, Spain
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		
08:30 - 08:50	Porphyria, Insights on New Treatment	Dr. Nadia Alhashmi, Oman
08:50 - 09:10	Insights on Urea Cycle Defects	Dr. Noura Aldhaheeri, UAE
09:10 - 09:30	Genetics Role in Intensive Care Management	Dr. Fatima Rabea, UAE
09:30 - 09:50	Symposium 3 Biomarin - Taiba Access Rare Symposium Achondroplasia: From Pathophysiology to Targeted Therapy	Dr. Sareea Al Remeithi, UAE
09:50 - 10:00	Q & A / Panel Discussion	
10:00 - 10:15	Coffee Break	
10:15 - 10:35	Symposium 4 - Immedica Unlocking the Mystery: A Rare Disorder as a Treatable Cause of Spastic Diplegia	Dr. Amal Altenaiji, UAE
Session 6: Treatable Metabolic Disorders Chair: Dr. Dalia Alraei Said & Dr. Heba Elabd		
10:35 - 10:55	Vitamin Responsive Disorders	Dr. Tawfeg Ben Omran, Qatar
10:55 - 11:15	CTX, Rare Cause of Adult Neurological Disease	Dr. Arif Khan, UAE
11:15 - 11:35	The New Landscape for Precision Medicine	Dr. Theodore W. Laetsch, USA
11:35 - 11:55	From Genetics to Hemodynamics: Hereditary Pediatric Pulmonary Hypertension from Genetic Perspective	Dr. Ahmed Adel Hassan, UAE
11:55 - 12:15	Symposium 5 - Biologics Recognize Early, Act Early: Transforming Alpha-Mannosidosis Care	Dr. Fatma Al Jasmi, UAE
12:15 - 12:30	Q & A / Panel Discussion	
12:30 - 13:30	Lunch Break & Prayer	
13:30 - 14:00	Symposium 6 - AstraZeneca Topic: Moderator: Dr. Maryam Al Shehhi, UAE	





CONGRESS AGENDA

Day 2 | Sunday | September 20
Le Meridien Dubai Hotel



TIME	TOPICS	SPEAKER
Session 7: Genetics Chair: Dr. Waed Sumairi & Dr. Sara Alsuwaidi		
14:00 - 14:20	The Role of Family Physician in Genetic Era	Dr. Aisha Abdullah, UAE
14:20 - 14:40	Obesity, Genetic Perspective	Dr. Asma Deeb, UAE
14:40 - 15:00	Skeletal Dysplasias and Growth Hormone	Dr. Zulf Mughal, UAE
15:00 - 15:20	Cincinnati Children's Rare Disease Program	Dr. Anne Slavotinek, USA
15:20 - 15:40	Symposium 7 - Biogen The New Era of SMA Care "Think High Dose: Higher & Faster"	Dr. Mehtab Iqbal, UAE
15:40 - 16:00	Q&A / Panel Discussion	
16:00 - 16:10	Coffee Break	
Session 8: Ethics & Research Chair: Dr. Fatma Aljasmí & Dr. Eman Taryam Alshamsi		
16:10 - 16:30	Ethics meets Genetics	Dr. Moeen Alsayed, KSA
16:30 - 16:50	What's Next When Genetic Testing is Negative? Expanding the Diagnostic Frontier Through Functional Genomics and Multi-Omics	Dr. Hiba Alblooshi, UAE
16:50 - 17:10	Interpretation of Genetic Results, Cases	Dr. Heba Elabd, UAE
17:10 - 17:20	Q & A / Panel Discussion	
17:20	End of Congress	





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POSTER PRESENTERS





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CAPTURED MOMENTS:

Highlights from the UAE Rare Disease Society's Past Conferences





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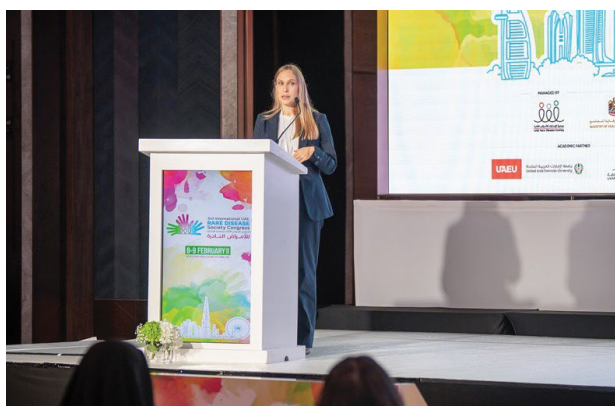




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Category	Physical
☐ Doctors	AED 900
☐ Nurses	AED 600
☐ Medical Students, Residents & Allied Health	AED 350
☐ Family Day (Parents/Guardians and 1 Kid)	AED 1000
☐ Pre Congress Workshops (Per workshop)	AED 500

A confirmation email will be sent upon receipt of your registration form. Please note that full payment must be received prior to the event. Payment can be made via Online, Credit card, Cheque, Bank drafts in AED.

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For more information, please contact

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Ph : +971 2 4919888, Mob : +971 56 503 3781
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Cancellation / Substitution Policy

If you are unable to attend, a substitute delegate will be very welcome in your place. If this is not suitable, a 20% administration fee will apply. Registrations cancelled less than one weeks before the event are non refundable.

Event Venue

Le Meridien, Dubai

The organizing committee reserves the right to make any modifications to the programme in occurrence of any unforeseen circumstances.



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PRE-CONGRESS WORKSHOPS

18 SEPT 2026

CONGRESS

19-20 SEPT 2026



Le Meridien Dubai Hotel, UAE



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