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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



CONFERENCE BOOK

Academic Partners



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INDEX

3 WELCOME MESSAGE	4 - 5 SCIENTIFIC AND ORGANIZING COMMITTEE
6 - 7 CONFERENCE OBJECTIVES, KEY POINTS, CONGRESS HIGHLIGHTS AND TARGET AUDIENCE	
8 - 9 WORKSHOP SPEAKERS	10 - 12 SPEAKERS
13 - 14 FAMILY DAY SPEAKERS	15 MODERATORS
16 GENERAL INFORMATION, CME ACCREDITATION AND CERTIFICATE OF ATTENDANCE	
17 PRE-CONGRESS WORKSHOPS	18 - 19 FAMILY DAY AGENDA
20 FAMILY DAY WORKSHOPS	21 - 24 CONGRESS AGENDA
26 - 50 ALL SPEAKERS' BIOGRAPHY	51 - 55 POSTER PRESENTERS
56 - 58 SPONSORS AND EXHIBITORS	



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 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



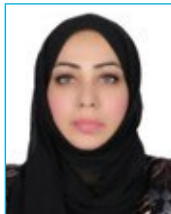
Dr. Amal AL Tenaiji
Consultant Clinical Geneticist,
Sheikh Khalifa Medical City



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



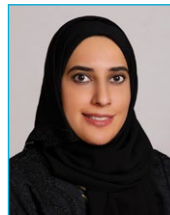
Dr. Badria Almurshidi
Specialist
Dubai Health Authority (DHA),
Dubai, UAE



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





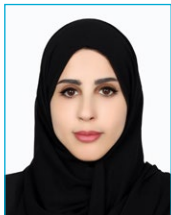
ORGANIZING COMMITTEE



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.

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



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.



WORKSHOP SPEAKERS



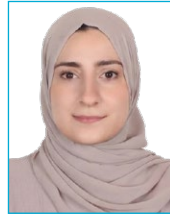
Ms. Masooma Al Jasmi
Head of Clinical Nutrition
Al Jalila Children's Specialty Hospital,
Dubai, UAE




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



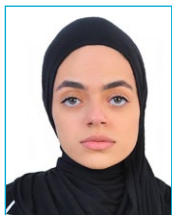

Dr. Azza Attia
Clinical geneticist,
Head of Clinical Genomics
G42, Abu Dhabi, UAE




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 hero, 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
HPP hero family member,
Bahrain




Mrs. Khadija Ismaeel
HPP hero family member,
Bahrain



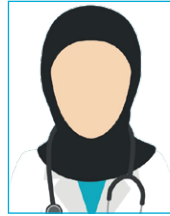

Ms. Dania Rahmoun
HPP hero, UAE




WORKSHOP SPEAKERS



Mrs. Nozhaa Al Masri
HPP hero family member,
UAE

Mrs. Arwa Alameri
HPP hero, UAE




Mrs. Jamila Qasim
HPP hero, UAE




Dr. Shaden Abdelhadi
Consultant Pediatric Dermatology
Adjunct Professor of Dermatology,
Khalifa University
Sheikh Khalifa Medical City,
Abu Dhabi, UAE




Ms. Chaza Alaa Eddin
Chaza Alaa Eddin, BSN, IIWCC-RN
Nurse Consultant | Dermatology &
Wound Care Nurse
Sheikh Khalifa Medical City (SKMC),
Abu Dhabi, UAE




Mr. Imti Rafiq
Youth Advocate, DEBRA
International Youth Council;
IT & EdTech Manager, UAE School;
EB Advocate, UAE




Ms. Salama Ali Al Nuaimi
Lawyer
Member, UAE Rare Disease Society




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



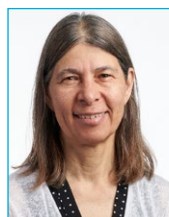
Dr. Leslie Lehmann
Director, Clinical Stem Cell
Transplantation Program
Medical Director, International
Hematology/Oncology/BMT
Associate Professor,
Harvard Medical School



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





SPEAKERS



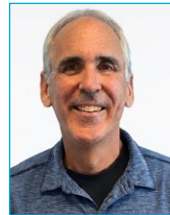
Prof. Fatma Al Jasmi
MBBS, FRCPC, FCCMG
Dean of CMHS, UAEU
Biochemical Genetics Consultant,
Tawam Hospital



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
Professor, University of Pittsburgh
School of Medicine
University of Pittsburgh School
of Medicine, 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



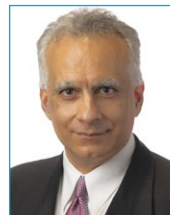
Dr. Fatma Ali Rabea
PhD, Mohammed Bin Rashid University
of Medicine and Health Sciences (MBRU)
Senior Clinical Scientist,
Dubai Health, UAE



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

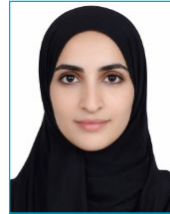




FAMILY DAY SPEAKERS



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



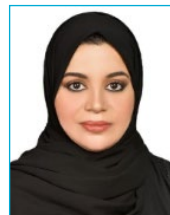
Ms. Shamsa Almheiri
Acting Head of the POD Friendly
Government Entity - Government
of Dubai Legal Affairs Department



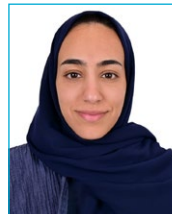
Ms. Eiman Jassim Al Ali
Specialist
People of Determination Support Programs
at the UAE Ministry of Family



Mr. Khaled Al Abdouli
Director - Wahat Al-Rushd
Sharjah, UAE



Dr. Fatima Ali Al Marzouqi
Social Expert
Department of Social Services,
Sharjah



Ms. Nehad Al Hemeiri
POD Department
Community Development
Authority Dubai, UAE



Mr. Rashed Bin Haider
Child Protection Department
Community Development Authority,
Dubai, UAE



Dr. Nazem Almanssour
People of Determination and
Senior Citizens Empowerment Expert
Ministry of Family



Dr. Abdulla Al Hammami
Assistant Specialist - Visual Impairment;
Family and Educational Consultant
Emirates Schools Establishment (ESE), UAE



Dr. Fatema AlHayyas
Family Guide - Dubai Courts



H.E. Dr. Eman AlHashmi
Founder and Chairperson
Autoimmune Association, UAE





FAMILY DAY SPEAKERS



Ms. Gabrielle Rosario
Product Manager, AI Office,
PureHealth, UAE




Dr. Fida Diyab
Founder of TAPY, and an advocate
dedicated to supporting mothers of
People of Determination and families
affected by rare diseases.






MODERATORS



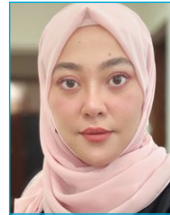
Dr. Fatima AbdulAziz
Consultant Pediatric-Clinical
Genetics and Genomics




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




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

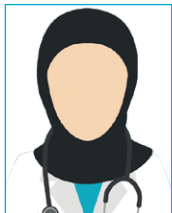
Dr. Faizah Hashimy
Specialist Physician – General Pediatrics,
with a clinical focus on metabolic disorders
Sheikh Khalifa Medical City,
Abu Dhabi - SEHA



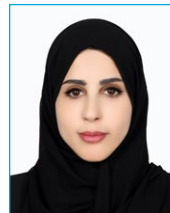

Dr. Halima Aldhanhani
Head of Pharmacy
Fujairah Hospital –
Emirates Health Services




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

Dr. Aysha Alabd
Consultant Family Medicine
Dubai Academic Health Care, UAE

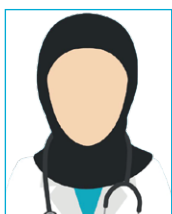
Ms. Dalal Al Dhabyani
Director of Operation
UAE Rare Disease Society




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




Mrs. Fouzia Alblooshi
UAE

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




Mrs. Nashemya Alfili
UAE Rare Disease




GENERAL INFORMATION

Venue

Le Méridien Dubai Hotel & Conference Centre is a 5-star urban resort located on Airport Road in Al Garhoud, Dubai, right next to Dubai International Airport.

Name Badges

Participants are required to wear their name badges throughout the meeting in order to be admitted to the lecture halls and other scheduled activities. Kindly ensure to scan in and scan out in the session halls attended.

Refreshment and Lunch

Refreshment and lunch will be offered in accordance with the breaks indicated on the Agenda.

Internet

Free internet will be available in the exhibition area during the conference.

Mobile Phones and Photography

Participants are kindly requested to keep their mobile phones silent mode in the conference hall and refrain from taking photographs with flash during sessions.

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).

- Pre-Congress Workshops, Friday 18/09/2026 is Accredited for 3.0 CME Hours
- DAY 1, Saturday 19/09/2026 is Accredited for 5.5 CME Hours
- DAY 2, Sunday 20/09/2026 is Accredited for 6.5 CME Hours

The 4th International UAE Rare Disease Society Congress (MECMP-2026-005167) has been accredited by the Department of Health to provide the following CME Activity for healthcare professional and is designated for a maximum of, or up to 15:30 of DOH CME

- DAY 1, Saturday 19/09/2026 is Accredited for 7.10 CME Hours
- DAY 2, Sunday 20/09/2026 is Accredited for 8.20 CME Hours

CERTIFICATE OF ATTENDANCE

- For DOH CME, Delegates are required to claim their certificate through the DOH TAMM application.
- The certificate can be claimed within 60 days from the conference start date, after this period certificates will no longer be available for claim
- Please ensure to scan in your name badge before every session in the session halls attended.
- CME points are accumulated based on attended hours.
- A notification containing the link and instructions on how to download the certificates will be sent to your registered email address.
- Please note that you are required to complete the online evaluation of the conference before you can access the link to download your CME certificates. It is your responsibility to download and retain a copy of the certificate for your records.
- Each medical specialist should claim only those credits that he/she actually spent in the educational activity.



PRE-CONGRESS WORKSHOPS

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



13:00-13:50 Registration	
13:50-14:00 Welcome & Introduction	
Wasl 4	Wasl 5
14:00-15:00 Workshop 1: Diet as Management of Rare Diseases Instructor: Ms. Masooma Al Jasmi, UAE	14:00-15:00 Workshop 2: Genetic Counselling in Rare Diseases: Principles and Practice Instructor: Dr. Richa Soni, UAE
Wasl 4	Wasl 5
15:00-16:00 Workshop 3: Metabolic Emergency Management Instructors: Dr. Mahra Al Fattah & Dr. Dalia Ra'a Said, UAE	15:00-16:00 Workshop 4: Genetic Testing Results: How to Interpret? Instructor: Dr. Azza Attia, UAE
16:00-16:15 Coffee Break	
Wasl 4	Wasl 5
16:15-17:15 Workshop 5: Approach to Bleeding Disorders Instructor: Dr. Eman Alshamsi, UAE	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 (Great Ballroom 3) 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 - استشاري علم الوراثة السريرية وعلم الجينوم - مستشفى توام د. سعاد العوز - وزارة الصحة ووقاية المجتمع سعادة القاضي / د. علي الخياصي - قاضي تمييز أول - محاكم دبي Dr. Ali Al-Beshri - Consultant Clinical Genetics & Genomics- Tawam Hospital Dr. Suad Alawar- MOHAP - His Excellency Judge / Ali Elthabahi - Senior Judge in Cassation - Dubai Court
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 (Great Ballroom 3) Session 2: From Hope to Impact: Initiatives that Changed the Lives of the Rare's من الأمل إلى التأثير: مبادرات غيرت حياة النادرين Chair: Mrs. Nafisa Tawfiq - Dr. Azhar Talal		
10:35-10:45	كلمة الترحيب لبرنامج العائلة Welcome & Introduction	Mrs. Nafisa Tawfiq - UAERDS Chairperson
10:45-11:05	جمعية أطفال القمر بالمغرب Association moon voice - Morocco	السيد 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	السيدة / صبحه الشامسي Mrs. Sabha Al Shamsi
11:15-11:35	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	ما بعد التشخيص الوراثي Beyond Genetic Diagnosis	د. فاطمة عبد العزيز استشاري أطفال - أمراض الوراثة والجينوم Dr. Fatima Abdulaziz Consultant Pediatric-Clinical Genetics and Genomics
11:55-12:15	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 - مؤسس شركة تابي أمان ناشطة في مجال دعم امهات اصحاب الهمم والأمراض النادرة Dr. Fida Diyab - Founder of Tapy, and an advocate dedicated to supporting mothers of People of Determination and families affected by rare diseases.
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 (Great Ballroom 3) Session 3: POD Government Services Programs Chair: Mrs. Fouzia Alblooshi – Dr. Madiha Fathi		
13:15-13:35	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	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	نحو منظومة متكاملة لحماية الأطفال وأصحاب الهمم Towards an Integrated Protection Framework for Children and People of Determination	فاطمة المرزوقي خبيرة اجتماعية - دائرة الخدمات الاجتماعية بالشارقة الاخصائية/ نهاد الحميري إدارة أصحاب الهمم - هيئة تنمية المجتمع - دبي الاخصائي / راشد بن حيدر إدارة الطفل - هيئة تنمية المجتمع - دبي Dr. Fatima Al Marzouqi Social Expert, Department of Social Services, Sharjah 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 (Great Ballroom 3) Session 4: Quality of Life: Between Family Stability and Advances in Treatment Chair: Mrs. Nashemya Alfili – Ms. Dalal Al Dhabyani		
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
15:10-15:25	What to do When You're Waiting: How I Use AI to Ask Better Questions	السيدة / غابرييل روزاريو متخصصة في الذكاء الاصطناعي وبطلة نادرة Ms. Gabrielle Rosario AI Professional and Rare Disease Hero
15:25-16:25	Interactive Lecture on Marriage for People of Determination	د. ناظم المنصور - خبير تمكين أصحاب الهمم وكبار المواطنين - وزارة الأسرة Dr. Nazem Al Manssour - POD & Senior Citizen Empowerment Expert – Ministry of Family
16:25-17:00	جلسة نقاشية بعنوان زواج أصحاب الهمم بين الواقع والتحديات A Panel Discussion on the Marriage of People with Disabilities: Between Reality and Challenges	د. ناظم المنصور - وزارة الأسرة د. عبد الله الهمامي - مستشار أسري وتربوي د. فاطمة الهياس - موجه أسري - محاكم دبي Dr. Nazem Al Manssour - Ministry of Family Dr. Abdulla Al Hammami - Family & Educational Consultant Dr. Fatema Al Hayyas - Family Guide - Dubai Courts
17:00 - 17:15	Q & A / Panel Discussion أسئلة وأجوبة	
17:15	Sponsors Awarding & CLOSING & END OF DAY تكريم الرعاية - ختام برنامج يوم العائلة	



FAMILY DAY WORKSHOPS

Sunday | September 20
Le Meridien Dubai Hotel



Wasl 6

10:15-12:15

Family Workshop 1 By PTC:

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



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

Wasl 3

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:

1. Dr. Zahra AlSahlawi, Bahrain
2. Dr. Ahlam Al Marzooqi, UAE
3. Dr. Maryam Al Shehhi, UAE
4. Dr. Amal Altenaiji, UAE

HPP Heroes:

1. Mrs Zahra Abdulaal, Bahrain
3. Mrs. Jamila Qasim, UAE
4. Mrs. Arwa Qasim, UAE
5. Ms. Dania Rahmoun, UAE



تواصل HPP

Wasl 4

14:30-16:30

Family Workshop 2 By GenPharm:

Awareness Workshop on Epidermolysis Bullosa (EB)

Instructors: Dr. Shaden Abdelhadi, Ms. Chaza Ala Eddin, Mr. Imti Rafiq,
Ms. Salama Alnuaimi, Ms. Abrar Alothman



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 دائم

Living with EB in Adulthood

Presenter: Ms. Salama Alnuaimi – Ms. Abrar Alothman

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

الحياة مع انحلال البشرة الفقاعي

المقدمة: الأستاذة / 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 منظمة للمشاركين لمشاركة تجاربهم، ومناقشة التحديات، وتبادل الخبرات والطول 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



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 (Great Ballroom 1) 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 - استشاري علم الوراثة السريرية وعلم الجينوم - مستشفى توام د. سعاد العور - وزارة الصحة ووقاية المجتمع سعادة القاضي / د. علي الخبازي - قاضي تمييز اول - محاكم دبي Dr. Ali Al-Beshri - Consultant Clinical Genetics & Genomics- Tawam Hospital Dr. Suad Alawar- MOHAP - His Excellency Judge / Ali Elthabahi - Senior Judge in Cassation - Dubai Court
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	
MAIN HALL (Great Ballroom 1) Session 2: Innovation in Rare Disease Chair: Dr. Amal Al Tenaiji & Dr. Noor Almeheri		
10:35 - 10:55	Porphyria, insights on new treatment	Dr. Nadia Alhashmi, Oman
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 ةطارتسا	
12:15 - 13:15	Lunch Break & Prayer	
MAIN HALL (Great Ballroom 1) Session 3: Metabolism and Biochemical Genetics Chair: Dr. Amel Aljasmi Almaeenei & Dr. Noura Aldhaheri		
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 قلاصلا ةطارتسا	
14:45 - 15:00	Coffee Break قلاصلا ةطارتسا	
15:00 - 15:20	Symposium 2 GenPharm - FAODs: When Fat Can't Fuel	Dr. Amal Altenaiji, UAE



CONGRESS AGENDA

Day 1 | Saturday | September 19
Le Meridien Dubai Hotel



TIME	TOPICS	SPEAKER
MAIN HALL (Great Ballroom 1) 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 (MAIN HALL-Great Ballroom 1) Session Chair: Dr. Mahra Alfattan & Dr. Ali Al-Beshri		
08:30 - 08:50	Beyond the hospital: Taking rare disease care home	Dr. Hamda Abulhoul, UAE
08:50 - 09:10	Insights on Urea Cycle Defects	Dr. Noura Aldhaheeri, UAE
09:10 - 09:30	Genetics Role in Intensive Care Management	Dr. Fatma Ali 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 (MAIN HALL-Great Ballroom 1) 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 - Biologix 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 HPP Patient Experience Moderator: Dr. Maryam Al Shehhi, UAE	



CONGRESS AGENDA

Day 2 | Sunday | September 20
Le Meridien Dubai Hotel



TIME	TOPICS	SPEAKER
Session 7: Genetics (MAIN HALL-Great Ballroom 1) Moderator: Dr. Waed Sumairi		
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	Re-thinking Growth Promotion in Skeletal Dysplasias	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 (MAIN HALL-Great Ballroom 1) Chair: Dr. Fatma Aljasmi & 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	





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

SPEAKERS' BIOGRAPHY





WORKSHOP SPEAKERS' BIOGRAPHY



Ms. Masooma Al Jasmi

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



Ms. Masooma Al Jasmi is the Head of Clinical Nutrition at Al Jalila Children's Specialty Hospital, Dubai, UAE, with extensive experience in pediatric clinical nutrition. Her areas of expertise include neonatal and pediatric nutrition, inborn errors of metabolism, ketogenic dietary therapy, cystic fibrosis, diabetes, celiac disease, food allergies and intolerances, inflammatory bowel disease, renal disorders, and obesity.



Dr. Richa Soni

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



Dr. Richa Soni is a Clinical Geneticist and Paediatrician currently practicing as Specialist Clinical Geneticist at Al Qassimi Women and Children's Hospital, Sharjah, UAE. She holds a Doctorate in Medicine in Medical Genetics from AIIMS, New Delhi, and an MD in Paediatrics and MBBS from IGMCI, Shimla, India. Her clinical practice centers on rare genetic disorders, reproductive genetics, and foetal autopsy, with expertise in genomic test interpretation, dysmorphology, and neurogenetic and metabolic disorders. She has established specialty genetics clinics across prenatal, paediatric, metabolic, cardiogenetic, and cancer genetics services at multiple institutions in India, including founding a Rare Disease Clinic with enzyme replacement therapy programmes.



Dr. Mahra Al Fattan

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



Dr. Mahra Fattan is a currently fellow in genetic/metabolic service in Tawam Hospital, Seha. She graduated in 2018 from the faculty of medicine & health sciences from the United Arab Emirates University. Following graduation, she trained and practiced in Tawam hospital, where she acquired the Arab Board diploma of medical specialization in pediatrics, in addition to passing MRCPCH certification and Emirati Pediatric Board. Dr. Fattan has been part of several of on-going collaborative research projects at Tawam hospital, and college of medicine.



WORKSHOP SPEAKERS' BIOGRAPHY



Dr. Dalia Ra'a Said

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



I am Dalia Ra'a Said, a Clinical Genetics and Metabolic Fellow at Tawam Hospital. After completing medical school, I joined the Pediatric Residency program. I am a triple board certified pediatrician with Arab board, Jordanian board, and Emirati board. Currently, I am actively contributing to the Genetics and Metabolic Department, where I strive to diagnose and treat the rarest of diseases, bringing hope to patients and families. My passion extends to genomic research, focusing on uncovering the most common genetic diseases and mutations prevalent in our population. By identifying these patterns, I aim to pave the way for targeted gene therapies that could transform treatment options and outcomes. As a dedicated physician and researcher, I am committed to advancing the field of medical genetics and improving the lives of those affected by rare and complex conditions.



Dr. Eman Taryam AlShamsi

MBBS, RCPCH
Consultant Pediatric
Hematologist Oncologist,
Dubai, UAE



Dr. Eman Taryam AlShamsi was working as Consultant and the Head of the Pediatric Hematology Oncology Department at Al Jalila Children's Specialty Hospital. Clinical Assistant Professor of Oncology at Mohammed Bin Rashid University of Medicine and Health

Sciences (MBRU) from August 2023 until 31 January 2026.

She graduated in 2002 from the Faculty of Medicine & Health Sciences at the United Arab Emirates University.

After graduation, Dr. AlShamsi trained and practiced at Tawam Hospital, UAE, from 2005. She served as staff from January 2017 until June 2021 when she joined Al Qassimi Women and Children Hospital (AQWCH) as a Consultant in Hematology Oncology and Head of Department. In August 2023, she moved to Al Jalila Children's Specialty Hospital, taking on her current role.

Dr. AlShamsi holds the Arab Board Diploma of Medical Specialization in Pediatrics and a diploma from the Royal College of Paediatrics and Child Health (RCPCH). She also obtained a Diploma in Clinical Research affiliated with the Vienna School of Clinical Research. She completed her clinical fellowship in Pediatric Hematology Oncology and Bone Marrow Transplant at SickKids Hospital in Toronto, Canada. This fellowship included training in Pediatric Clinical Hematology Oncology, Bone Marrow Transplant, and Thrombosis. Additionally, she attended an administrative fellowship program at MD Anderson Cancer Center in Texas, USA.

Throughout her career, Dr. AlShamsi has been involved in several ongoing collaborative research projects at Tawam and AQWCH hospitals, MBRU, UAEU, and Zayed University, with publications on PubMed. She has authored and reviewed chapters on bleeding disorders and pediatric cancers for upcoming medical textbooks.

Dr. AlShamsi hosted the SIOP Asia Conference in Abu Dhabi in April 2019. She actively participates in numerous national and international committees and activities, including the Scientific Sub-Committee of the International Medical Awards 2023-2024 (Sheikh Hamdan Bin Rashid Al Maktoum Award for Medical Science), the Transfusion Committee at AQWCH/AQH, and the NIHS Pediatric Hematology Oncology Accreditation (Head of the Sub-Committee). She is also involved in national bone marrow transplants, cancer screening, and prevention initiatives, as well as the SIOP and Women Leaders in Pediatric Oncology (WLPO). Her patient support and awareness activities include work with CCI and Friends of Cancer Patients UAE (FOCP). In recognition of her contributions, Dr. AlShamsi received the EOS Cancer Awareness Advocate of the Year 2024 Award from the Emirates Oncology Society.

WORKSHOP SPEAKERS' BIOGRAPHY



Dr. Azza Attia

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



Dr. Azza Attia is a European Board-certified Consultant in Medical Genetics with more than two decades of experience in clinical, molecular, and chromosomal genetics. She currently serves as Head of Clinical Genomics at M42 in Abu Dhabi, UAE, where she contributes to the development and implementation of genomic medicine and genetic testing programs. Her expertise includes rare genetic disorders, dysmorphology, next-generation sequencing, phenotype-genotype correlation, clinical reporting, and genetic counseling. Dr. Attia has extensive international experience spanning France, Egypt, and the UAE, and has contributed to clinical care, medical education, research, and large-scale genomic initiatives. She also holds academic appointments at UAE University and Ain Shams University.



Dr. Badria Almurshidi

Specialist
Dubai Health Authority (DHA),
Dubai, UAE



Dr. Badria Hassan Almurshidi is an Emirati clinical scientist and academic specializing in medical education, clinical research, nanomedicine, and molecular toxicology. She currently serves as a Specialist Doctor in the Medical Education and Research Department at Dubai Health Authority (DHA), contributing to healthcare education, research development, and evidence based practice.

She previously worked as an Assistant Professor at United Arab Emirates University (UAEU), where she was actively involved in teaching, research supervision, and scientific publications. Dr. Almurshidi holds a PhD in Environmental Health with a focus on nanomedicine from the University of South Carolina and a Master's degree in Molecular Toxicology from Oregon State University. Her work reflects a strong commitment to advancing medical education and translational research within the UAE



Ms. Fatemah Al Awadhi

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



Fatemah is a PICU, NICU & Inborn Errors of Metabolism dietitian based in Farwaniya Hospital with 6 years of experience in Pediatrics.

Got her diploma from the Public Authority of Applied Training in Kuwait & continued her studies in the University of Florida in clinical dietetics.

Interned in King Abdullah Specialized Hospital based in Riyadh where she got her metabolic dietitian training



WORKSHOP SPEAKERS' BIOGRAPHY



Dr. Zahra Alsahlawi

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



Consultant pediatric / inborn error of metabolism and clinical genetic

Pediatric department – salmaniya mediocl hospital – kingdom of Bahrain

Chief of medical staffs for medical departments at government hospitals

Had the training of metabolic and genetic in King Faisal specialist hospital and research center in Riyadh and in Manchester Center for genomic medicine (Willink biochemical genetics unit) Manchester – UK

Assistant Professor at pediatric department – Arabian Gulf University

Works as the only metabolic consultant for pediatric and adult for all hospitals in Bahrain



Dr. Ahlam Al Marzooqi

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



Dr. Ahlam Mohamed Abdulla Almarzooqi is a Consultant Rheumatologist and Internal Medicine Consultant at Al Qassimi Hospital, Emirates Health Services, UAE. She is an Adjunct Clinical Assistant Professor at the University of Sharjah. She holds MRCP (UK), the Arab Board in Internal Medicine, the Jordanian Board in Rheumatology, and the Specialty Certificate Examination in Rheumatology (UK). She is actively involved in clinical practice, medical education, research, and the management of complex rheumatic and musculoskeletal diseases.



WORKSHOP SPEAKERS' BIOGRAPHY



Dr. Shaden Abdelhadi

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



Dr. Shaden Abdelhadi is a Pediatric Dermatology Consultant, European Board and Arab Board Certified in Dermatology & Venereology, Belgian Board Certified in Pediatric Dermatology (including clinical training at Seattle Children's Hospital, Seattle, USA). She holds the Belgian Board in Human Medical Genetics from the Belgian Society of Human Genetics BeSHG (including training at Guys & St. Thomas Genetic Skin Diseases Center in London, UK). Moreover, she is a Fellow of the Royal College of Physicians of Edinburgh (FRCP Edin).

She is also the Director of the ACGMEi accredited Dermatology Residency Program at Sheikh Khalifa Medical City, Abu Dhabi.

Dr. Shaden holds the distinction of being the first fully licensed Pediatric Dermatologist in Abu Dhabi.

She has been highly active in academics since 2012 including active teaching and supervision in her specialties in both Belgium and the UAE.

Dr. Shaden Abdelhadi is an Assistant Professor of Dermatology at College of Medicine and Health Sciences, Khalifa University in Abu Dhabi. In 2021, she was appointed as a founding committee member and section chair, National Institute of Health Sciences (NIHS) for the Emirati Board of Dermatology.

Moreover, she is the founder and head of the Multidisciplinary Epidermolysis Bullosa Center at SKMC.

Additionally, she is a Fellow of the American Academy of Dermatology (FAAD), the European Academy of Dermatology and Venereology (FEADV) and the European Society of Pediatric Dermatology (FESPD).

Dr. Shaden is a Member of the Editorial Board of the Dermatologic Therapy, a John Wiley & Sons Ltd. journal.



Ms. Chaza Alaa Eddin

Chaza Alaa Eddin, BSN, IIWCC-RN
Nurse Consultant | Dermatology &
Wound Care Nurse
Sheikh Khalifa Medical City (SKMC),
Abu Dhabi, UAE



Chaza Alaa Eddin, BSN, IIWCC-RN, is a registered Nurse at Sheikh Khalifa Medical City (SKMC), Abu Dhabi, where she has been serving as a Registered Nurse since 2004. Since 2010, she has specialized in dermatology and wound care, with extensive experience in wound assessment, evidence-based wound management, patient education, and nursing professional development.

Chaza is committed to advancing nursing practice through education, quality improvement, and clinical excellence. Her dedication has been recognized with the DAISY Award Honoree (2025) and the Best Nurse Care Award (2024 & 2026).

She is passionate about sharing practical knowledge and empowering nurses to deliver high-quality, patient-centered wound and dermatology care.



WORKSHOP SPEAKERS' BIOGRAPHY



Mr. Imti Rafiq

Youth Advocate, DEBRA
International Youth Council;
IT & EdTech Manager, UAE School;
EB Advocate, UAE



Mr. Imti Rafiq is a dedicated youth and patient advocate supporting the Epidermolysis Bullosa (EB) community in the UAE and internationally. He serves on the DEBRA International Youth Council and works as an IT & EdTech Manager at a UAE school. Through his advocacy, he helps raise awareness, amplify youth voices, and support individuals and families affected by EB.



Ms. Salama Ali Al Nuaimi

Advocate living with EBS



Salama Ali Al Nuaimi is a member of the UAE Rare Disease Society and lives with Epidermolysis Bullosa Simplex (EBS). She graduated with a degree in Public Law from Al Ain in 2016 and has been practicing as a lawyer since 2020. Through her personal and professional journey, she brings a strong perspective on resilience, inclusion, and the importance of raising awareness about rare diseases.



Ms. Abrar Al Othman

Media Personality & Influencer; Author
& Epidermolysis Bullosa (EB) Advocate,
Saudi Arabia



She is a writer for Sayidaty Magazine and the author of four books. She has received several local and international awards and recognitions and was nominated for the Joy Awards.

She has been featured in numerous interviews with international newspapers and global media platforms and was selected among the most beautiful faces in the world, appearing on the cover of Vogue Arabia.

She has also participated in various health forums, conferences, and events, contributing to awareness and advocacy in the healthcare field.

كاتبة في مجلة سيدتي، مؤلفة لـ 4 كتب، حاصلة على عدة جوائز وتكريمات محلية ودولية وترشحت لجائزة الـ joyawards، ظهرت في عدة لقاءات ملها صحف ومطبوعات عالمية وتم إختيارها ضمن أجمل وجوه العالم على غلاف مجلة VOUGE العربية، شاركت عدة ملتقيات ومؤتمرات صحية □ □

SPEAKERS' BIOGRAPHY



Dr. Ali Al-Beshri

Consultant Clinical
Genetics & Genomics
Tawam Hospital, Al Ain,
Abu Dhabi, UAE



Dr. Ali Al-Beshri is a Consultant Physician with triple US board certification in Internal Medicine, Medical Genetics and Genomics, and Medical Biochemical Genetics. After completing his combined residency at the University of Alabama at Birmingham (UAB), he undertook a fellowship in Medical Biochemical Genetics at the National Institutes of Health (NIH/NHGRI). During his tenure as Assistant Professor at UAB, Dr. Al-Beshri co-established Alabama's first adult cardiogenomics and mitochondrial disease clinics. He currently practices in the Division of Genetics at Tawam Hospital and serves as Adjunct Faculty at UAB.



Dr. Suad Alawar

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



A public health expert and Family Medicine consultant with over 29 years of experience, including 12 years in clinical practice and 17 years in national technical leadership, holds the Arab Board in Family Medicine and a medical degree from United Arab Emirates University. The professional journey started in maternal and child health centers in Al Ain and Dubai and progressed to senior leadership positions, including Acting Director of Preventive Medicine and Director of Primary Healthcare in Dubai. Since 2021, has been leading the Family Health Section at the Ministry of Health and Prevention, driving the development and implementation of national strategies and programs across family health, maternal, neonatal, child and adolescent health, school and elderly health, and the health response to violence. Contributions include overseeing national surveys, chairing key committees, advancing quality standards, and playing a pivotal role in the COVID-19 response, including supervision of health centers, epidemiological investigations, and vaccination programs. Representing the country in regional and international forums.



Dr. Ali Elthabahi

Judge and Head of the Personal
Status Appeals Circuit
Dubai Courts, UAE



Dr. Ali Abdullah Ali Bin Eissa Al Thabahi is a Senior Appeals Judge at Dubai Courts, with extensive judicial experience since 2002 across civil, commercial, real estate, criminal, labor, and personal status cases. He previously served as Head of the First Personal Status Appeals Circuit and has held several judicial and administrative roles. He holds a PhD in Islamic Jurisprudence and Contemporary Social Issues from Mohammed V University in Abu Dhabi, a Master's in Endowment Studies from Zayed University, and qualifications in forensic sciences, Sharia, and law. He is also a certified professional trainer and has trained judges, legal professionals, and students. Dr. Al Thabahi has contributed to numerous academic seminars, conferences, and research initiatives, particularly in Islamic jurisprudence, UAE personal status law, and family matters. He has received several recognitions, including the Distinguished Judge title from Dubai Courts.



SPEAKERS' BIOGRAPHY



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


Nafisa Tawfiq currently serves as Chair President of the UAE Rare Disease Society. She is a Biochemistry graduate of UAE University in Al Ain and brings 22 years of professional experience from the Dubai Genetics Centre, Pathology and Genetics Department, Dubai Health Authority, where she served as Head of the Metabolic Genetics Unit. Her strong academic background, combined with many years of practical experience as a Chief Laboratory Technologist, has provided her with extensive knowledge and expertise in laboratory diagnostic testing for rare genetic and metabolic disorders. Through her leadership and professional experience, she continues to contribute to the advancement of rare disease awareness, diagnosis, and support for affected individuals and families.



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


Dr. Hamda Abulhoul is a Consultant in Pediatric Inherited Metabolic Medicine at Al Jalila Children's Hospital, Dubai Health, UAE. She graduated from Edinburgh Medical School in 1995 and completed her postgraduate training in the United Kingdom, becoming a consultant in 2005. From 2008 to 2016, she worked as a Consultant in Metabolic Medicine at Great Ormond Street Hospital in London, where she also served as Clinical Lead for the metabolic department, with a focus on patient experience and safety. Dr. Abulhoul moved to the UAE in 2016 and has since continued her clinical practice in Dubai. Her expertise includes the diagnosis and management of inherited metabolic disorders and inborn errors of metabolism in children.

SPEAKERS' BIOGRAPHY



Dr. Osama Aldirbashi

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



Dr. Osama Aldirbashi is a Senior Consultant Clinical Scientist at the Metabolic lab, Department of Lab Medicine and Pathology, Hamad Medical Corporation, Doha, Qatar. He is also a Clinical Professor, College of Health Sciences, Qatar University and a Professor (adjunct), College of Health & Life Sciences, Hamad Bin Khalifa University, Doha, Qatar.

Dr. Aldirbashi is a clinical biochemical geneticist certified by the American Board of Medical Genetics and Genomics, the Canadian College of Medical Geneticists and the European Board of Medical Genetics. He attended graduate school at Nagasaki University and completed fellowship training at the Children's Hospital of East Ontario, University of Ottawa. Dr. Aldirbashi received specific biochemical genetics training at Toronto, Calgary, London and San Diego. His expertise spans newborn screening, inborn errors of metabolism, mass spectrometry, development of new lab tests and metabolomics biomarker discovery.

During his career, Dr. Aldirbashi led major screening and diagnostic labs in North America and the Middle East where he was instrumental in refining testing methodologies, devolving new screening algorithms, and establishing new screening programs. He was appointed as faculty at medical schools in the Middle East and Canada where he supervised numerous graduate students as well as trainees, fellows and residents. He received several grants and published more than 70 articles in prestigious journals including Pediatrics, Human Genetics, Genetics in Medicine, Clinical Chemistry, Analytical Chemistry, Journal of Inherited Metabolic Disease and others. Throughout his career, Dr. Aldirbashi volunteered on various editorial boards and committees including the International Journal of Neonatal Screening and the Canadian College of Medical Geneticists.



Dr. Amal Mohammed Alhashem

Consultant/ Professor/
Chairperson Genetic Department
King Fahad Specialist Hospital-
Alfaisal University, Saudi Arabia



Prof. Amal Alhashem is a Consultant Pediatrician specializing in Clinical Genetics and Metabolic Medicine. She serves as the consultant at king fahad specialist hospital -dammam. Additionally, she is a Professor of Genetics at Alfaisal University, and holds the position of Head of the Genetic Department at Seha Virtual Hospital, as well as the Head of Genetic Centers in the Ministry of Health. Dr. Alhashem is the Head of the Scientific Committee for the Birth Defect Registry in the Saudi Health Council. She has authored over 120 papers and is particularly interested in the Birth Defect Registry and population awareness and prevention.

SPEAKERS' BIOGRAPHY



Dr. Amal AL Tenaiji

Consultant Clinical Geneticist,
Sheikh Khalifa Medical City



Dr. Amal completed her undergraduate studies at UAE University and graduated in 2006 with Bachelor in Medicine and Health Science. She then completed the paediatrics residency program at Sheikh Khalifa Medical City and successfully obtained the Arab Board Specialization in Paediatrics as well as the Membership of the Royal College of Paediatrics and Child Health (MRCPCH). She then continued and pursued further postgraduate studies at The University of Toronto, and Hospital for Sick Children, Canada. Subsequently, she completed a clinical fellowship in biochemical genetics. She obtained the Canadian Board in Clinical Biochemical Genetics. She is a teacher for many residents and Fellows and has several publications in the inborn errors of metabolism field.



Dr. Leslie Lehmann

Director, Clinical Stem Cell Transplantation Program
Medical Director, International Hematology/Oncology/BMT
Associate Professor, Harvard Medical School
USA



Dr. Leslie Lehmann is the clinical director of the Stem Cell Transplantation Program at Dana-Farber/Boston Children's Cancer and Blood Disorders Center. She specializes in bone marrow and stem cell transplantation and the long-term effects of stem cell transplantation. In addition, she is an assistant professor of Pediatrics at Harvard Medical School.



Dr. Encarna Guillen

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



Professor Encarna Guillén-Navarro is a specialist in medical genetics, pediatrics, precision medicine, and rare diseases. She serves as Head of Genomic Medicine and Strategic Director of UNICAS and is an Associate Professor of Pediatrics and Medical Genetics at the University of Murcia, Spain. She is also President of the Spanish Association of Human Genetics and Vice President of the Clinical Genetics Section of the European Union of Medical Specialists. Her clinical and research expertise includes syndromic and neurodevelopmental disorders, ectodermal dysplasias, achondroplasia, and porphyria.

Professor Guillén-Navarro has authored more than 150 peer-reviewed publications and several book chapters and has contributed to over 30 research grants and clinical trials related to genetic rare diseases. She has held leadership positions in pediatrics and medical genetics and has served on national scientific, research ethics, and bioethics committees. Her work continues to advance genomic medicine and care for people living with rare diseases.

Her international experience includes a clinical genetics fellowship at New York University Medical Center and Bellevue Hospital. She has also advised major European rare-disease initiatives and contributed as a World Health Organization expert to the genetics working group supporting development of the eleventh International Classification of Diseases for pediatric care.

SPEAKERS' BIOGRAPHY



Dr. Fatima Nuñez

Research Deputy Director
Sant Joan de Déu Barcelona
Children's Hospital, Spain



Dr. Fátima Nuñez Mangado is an expert in Medical Genetics, biomedical research, strategic leadership, healthcare innovation, and genomic and precision medicine, with a particular focus on pediatrics and rare diseases. She currently serves as Deputy Director of Innovation, Research and Learning at Sant Joan de Déu Barcelona and, since 2026, as Executive Director of the hospital's Advanced Therapies Programme.

Dr. Nuñez Mangado has held several leadership positions at the Vall d'Hebron Research Institute (VHIR) since 2005, including Coordinator of Core Facilities and Deputy CEO. She has extensive international scientific and healthcare management experience and currently serves on the Scientific Advisory Board of EATRIS, the Steering Committee of the European University Hospital Alliance (EUHA), and the European Children's Hospitals Association (ECHO).

She holds a PhD in Molecular and Cellular Biology from the University of Edinburgh, a degree in Genetics from Trinity College Dublin, and postgraduate qualifications in project management and healthcare leadership.



Dr. Anne Slavotinek

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



Dr. Anne Slavotinek is a geneticist who cares for patients of all ages with a wide range of genetic conditions, including rare diseases, congenital disabilities, and developmental anomalies. Her clinical and research interests focus on understanding the underlying causes of rare genetic disorders, with the goal of translating these discoveries into improved treatments and outcomes for patients.

Through her clinical practice, Dr. Slavotinek evaluates and manages patients while seeking additional resources and research opportunities for individuals and families with complex or undiagnosed conditions. She frequently collaborates with researchers and specialists to explore further diagnostic possibilities and gain new perspectives on challenging cases.

Her interest in medical genetics began after attending a seminar on the discovery of a new gene and a novel disease-causing mechanism. Inspired by the presentation and her experience working in a genetics research institute, she pursued clinical training in medical genetics and went on to build her career in the field.

Dr. Slavotinek serves as Director of the Division of Human Genetics and Professor in the UC Department of Pediatrics at Cincinnati Children's Hospital, USA. She is also a Co-Editor of the American Journal of Medical Genetics and a former Chair of the American Board of Medical Genetics and Genomics. Outside of her professional work, she enjoys spending time outdoors, a passion developed during her childhood in Australia.



SPEAKERS' BIOGRAPHY



Prof. Fatma Al Jasmi

MBBS, FRCPC, FCCMG
Dean of CMHS, UAEU
Biochemical Genetics Consultant,
Tawam Hospital



Prof. Fatma Al Jasmi is Dean of the College of Medicine and Health Sciences at United Arab Emirates University and Professor of Genetics & Genomics. A Consultant in Biochemical Genetics at Tawam Hospital, she trained in Pediatrics and Biochemical Genetics at the University of Toronto and is a Fellow of the Royal College of Physicians and Surgeons of Canada and the Canadian College of Medical Genetics. Prof. Al Jasmi is internationally recognized for her leadership in rare diseases, lysosomal storage disorders, and genomic medicine. She serves as Chair of the Middle East and North Africa Medical Genetics Association (MENA-MGA) and has received prestigious honors including the Prime Minister's Award for Excellence, the L'Oréal UNESCO Women in Science Award, and the Chancellor's Innovation Award.



Dr. Sareea Al Remeithi

Consultant Pediatric Endocrinology
Sheikh Khalifa Medical City,
Abu Dhabi, UAE



Dr. Sareea S. Al Remeithi is Division Chief of Pediatric Endocrinology and Director of the Pediatric Residency Program at Sheikh Khalifa Medical City (SKMC), Abu Dhabi. She is a Consultant Pediatric Endocrinologist with expertise in diabetes management, growth and puberty disorders, metabolic and endocrine diseases, and advanced diabetes technologies, including insulin pumps and continuous glucose monitoring. She completed her MBBS and pediatric residency training at UAE University, followed by a Clinical Fellowship in Pediatric Endocrinology at the University of Toronto's Hospital for Sick Children. She also holds advanced training in clinical research and epidemiology and is a Fellow of the Royal College of Physicians and Surgeons of Canada (FRCSC) and a Member of the Royal College of Paediatrics and Child Health (MRCPCH).



Dr. Hind Alsharhan

Assistant Professor of Pediatrics,
Medical and Biochemical Geneticist
Department of Pediatrics Kuwait University,
Faculty of Medicine, Kuwait



Dr. Alsharhan was certified by the American Board of Paediatrics in 2016, the American Board of Medical Genetics and Genomics (ABMG) in Medical Genetics and Genomics in 2019, the ABMG in Medical Biochemical Genetics in 2019, and the ABMG in Clinical Biochemical Genetics in 2021. Dr. Alsharhan has numerous publications in high-impact journals. She is supervisor and teachers for plenty of fellows, residents and medical students.

SPEAKERS' BIOGRAPHY



Dr. Gary Thomas

Professor, University of Pittsburgh
School of Medicine
University of Pittsburgh School
of Medicine, USA



Gary Thomas, PhD, is a professor at the University of Pittsburgh School of Medicine. His research focuses on mechanisms underlying PACS1 syndrome and related neurodevelopmental disorders. His laboratory discovered the PACS1 and PACS2 genes and defined how these proteins regulate membrane trafficking, proteostasis, calcium signaling, and gene expression. Building on these discoveries, his team identified mechanistic steps disrupted by the recurrent PACS1 p.Arg203Trp variant, linking altered protein trafficking and homeostasis to abnormal neuronal development and synaptic function. His laboratory was the first to demonstrate preclinically that antisense oligonucleotides can correct neuronal structural and functional deficits in models of PACS1 syndrome. These studies laid the groundwork for the ASO treatments now administered to patients with PACS1 syndrome at Pitt and UPMC. By integrating cell biology, biochemistry, animal models, and patient-derived systems, Dr. Thomas's program is building on this clinical progress to develop precise therapies for this devastating rare disorder.



Dr. Maryam Mohammed AL Shehhi

Consultant - Pediatrics Clinical Genetics
Sheikh Khalifa Medical City,
Abu Dhabi, UAE



Dr. Maryam Al Shehhi, is a consultant clinical geneticist at Sheikh Khalifa Medical city, Abu Dhabi and an adjunct associate professor of Genetics and Genomic Medicine at the UAE University, college of medicine and health sciences. She has many publications in medical genetics including new discoveries of rare disease genes. She is a member of the SEHA Genomics Service Line and a faculty trainer at UAEU Medical Genetics Fellowship training and Genetic Counselling Master course. Her areas of interest and research are rare genetic diseases, dysmorphology, skeletal dysplasia, neurodevelopment and neuromuscular disorders.



SPEAKERS' BIOGRAPHY



Dr. Nadia Alhashmi

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



Dr Nadia alhashmi Medical and biochemical geneticist, senior pediatric consultant I graduated from Sultan Qaboos university college of medicine 2001. obtained membership in pediatric MRCPH in 2006, obtained Oman medical specialist board in pediatric 2007, that was followed up by fellowship program for three years in medical genetic at king Faisal specialist hospital and research center Riyadh Saudi Arabia. I was recognized as the best fellow among my patch I have more than 14 years of clinical experience in medical genetic at Royal hospital which consider to be the main tertiary hospital in Oman with very heavy load of complex pediatric patients

I have main interest in larger molecular disorder selectively mitochondrial and lysosomal storage disease.

At our hospital we diagnosed more than 100 patients with picture of mitochondrial diseases, and more than 120 patients with lysosomal storage disease

We have more than 12 patients on enzyme replacement therapy.

I have special interest in prenatal diagnosis of inherited disease and complex fetal dysmorphism

2017 we established a new service to help family with inherited genetic disorder which is preimplantation genetic diagnosis (which helped more than 100 families to get healthy child

I have more than 34 publications in biochemical genetic and clinical genetic

I am involved in more than clinical research studies.



Dr. Fatma Ali Rabea

PhD, Mohammed Bin Rashid University
of Medicine and Health Sciences (MBRU)
Senior Clinical Scientist,
Dubai Health, UAE



A Senior Clinical Scientist at Dubai Health with a PhD in Biomedical Sciences from Mohammed Bin Rashid University of Medicine and Health Sciences. Over the course of my career, I have developed a strong interest in using genomics to improve the diagnosis and care of patients with rare genetic diseases. My work spans population screening, genomic diagnostics, and novel gene discovery, with a particular focus on translating genomic advances into clinical practice in the UAE. I have authored and co-authored peer-reviewed publications in the field of genomic medicine and rare diseases.



SPEAKERS' BIOGRAPHY



Dr. Noura Aldhaheeri

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



Noura AIDhaheeri is an Assistant Professor at the Department of Pediatrics, College of Medicine and Health Sciences (CMHS), UAE University. Dr. AIDhaheeri holds American Board of Pediatrics certification and is qualified in Medical Genetics & Genomics and Medical Biochemical Genetics.

Dr. AIDhaheeri obtained her pediatric residency training at Children's National Medical Center in Washington DC, USA (2012-2015) then training in Medical Genetics from Johns Hopkins School of Medicine and National Institute of Health in the United States (2015-2017). Following that, she completed Medical Biochemical Genetics Fellowship at Baylor College of Medicine and Texas Children Hospital in Houston, TX, USA in November 2018 and joined CMHS- UAE University as an Assistant Professor.

Dr. AIDhaheeri's current research focus is in Genomic Medicine, identification of candidate genes for undiagnosed rare disease, and AI applications for variant interpretations.



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



Prof. BEN-OMRAN is a senior consultant and Division Chief, Genetic and Genomic Medicine at Sidra Medicine and Hamad Medical Corporation. He is a Professor at Weill Cornell Medical College, Qatar & New York-USA. He is also a Distinguished Visiting Scientist at Boston Children's Hospital-USA.



Dr. Arif Khan

Section Head, Pediatric &
Neuro Ophthalmology
Cleveland Clinic Abu Dhabi, UAE



Arif O. Khan MD is Interim Chair of Ophthalmology and Section Head of Pediatric & Neuro-Ophthalmology at Cleveland Clinic Abu Dhabi, UAE, and Professor of Ophthalmology at Cleveland Clinic Lerner College of Medicine, USA. Previously, through the end of 2015, Dr. Khan was Senior Academic Consultant (Pediatric Ophthalmology & Strabismus) at the King Khaled Eye Specialist Hospital and Senior Scientist (Genetics) at the King Faisal Specialist Hospital & Research Center, both in Riyadh, Saudi Arabia. Before he moved to the Gulf region in January 2002, Dr. Khan was in private practice in New York. Dr. Khan's clinical and research interests are genetic eye disease and strabismus. He is a frequent invited speaker at international ophthalmology meetings and has authored hundreds of scientific publications related to his field.

SPEAKERS' BIOGRAPHY



Dr. Theodore W. Laetsch

Attending physician, Cancer Center
Children's Hospital of Philadelphia
(CHOP), USA



Dr. Theodore Laetsch is a pediatric oncologist and leads both the Developmental Therapeutics Program (DVL) and the Very Rare Malignant Tumors Program (VRMTP) at the Children's Hospital of Philadelphia, as well as holding national leadership roles in each of these areas within the Children's Oncology Group (COG).

In the DVL program, Dr. Laetsch conducts early phase clinical trials of new treatments for children with difficult to treat cancers, with a particular area of focus including molecularly targeted therapies that are designed to block specific genetic mutations identified in patients' tumors. In particular, Dr. Laetsch leads the pediatric development of TRK inhibitors for children with NTRK gene fusions, and now leads a COG nationwide clinical trial studying the ability to use TRK inhibitors instead of chemotherapy for children with one of these gene fusions.

While individually very uncommon, together very rare malignant tumors comprise over 10% of childhood cancers. Given the rarity of each individual diagnosis, these cancers have been poorly studied and for many patients there are not standard, defined treatments. As the chair of the Rare Tumors Committee for the Children's Oncology Group, Dr. Laetsch is working to advance the study of these tumors and define new ways to treat patients. Dr. Laetsch is hopeful that we can advance the care of patients with these tumors by using cancer genomics to identify targetable mutations as well as studying immunotherapy, which has revolutionized the care of many of these cancers in adult patients.

Finally, Dr. Laetsch is a member of the cellular therapy / chimeric antigen receptor (CAR) T-cell team at the Children's Hospital. Prior to joining the Children's Hospital in 2020, Dr. Laetsch led the pediatric CAR T-cell program at the University of Texas Southwestern Medical Center.

In each of these areas, Dr. Laetsch provides clinical care and conduct research, with an overarching goal of improving treatment options for children with difficult to treat cancers.



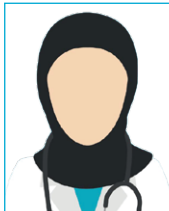
Dr. Ahmed Adel Hassan

Consultant Pediatric Cardiologist
Al Jalila Children's Heart Center,
Dubai, UAE



Dr Ahmed Adel Hassan is a Consultant Paediatric and Congenital Interventional Cardiologist at Al Jalila Children's Specialty Hospital, Dubai Health, with academic appointments at Mohammed Bin Rashid University of Medicine and Health Sciences and the University of Sharjah. He graduated in Medicine from Ain Shams University in 2008 and trained in paediatrics (MRCPCH 2014; Arab Board 2016) before subspecialty training in paediatric and congenital cardiology in Dubai. He holds the joint EACVI/AEPC diploma in congenital echocardiography (2022) and the AEPC certification examination (2024). He founded and leads the paediatric pulmonary hypertension service across three Dubai Health sites, caring for patients from premature neonates to adolescents. His interests include pulmonary vascular disease, interventional catheterisation in congenital heart disease, and equity of access to advanced pulmonary hypertension therapy.

SPEAKERS' BIOGRAPHY



Dr. Aisha Abdullah

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



Dr. Aisha Abdullah, Consultant family physician with special interest in fetomaternal medicine & sonography, Genetic & AI utilization in medical services.

Education:

- MBBS FMHS Al Ain 1995.
- Arab Board Family Medicine 2000.
- MRCGP (Int) Sultan Qaboos University Muscat 2007.
- Advanced obstetric & Gyn Ultrasound Diploma FMHS 2014. & Harvard business review reader.

I am working as Director of 13 health centers in Fujairah & recently a coordinator of public health services in Fujairah under EHS. I am practicing sonography in low-risk ANC clinic in PHC. I am proud that I lead the establishment of cancer screening in Fujairah in 2015 & recently I started initiation of deep analysis of obesity among children in PHC.



Dr. Asma Deeb

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



Prof Asma Deeb, Chair of Paediatric Endocrinology, Sheikh Shakhbout Medical City (SSMC), Abu Dhabi, United Arab Emirates. She is the Chair of research ethics committee at the SSMC and a clinical professor at the Gulf University and Khalifa University, UAE. Prof Deeb is the president of the Arab Society of Paediatric Endocrinology and Diabetes (ASPED). She is an executive board member at the Global Pediatric Endocrinology and Diabetes and the International Consortium of paediatric endocrinology.

Prof Deeb is an associate editor for Hormone Research in Paediatrics and Pediatric Diabetes and a reviewer for a large number of journals in paediatric endocrinology and diabetes. She is a keen researcher with a high number of publications.

She trained in the United Kingdom and had an MD degree on growth hormone gene expression from the University of Newcastle upon tyne in 2002. She pursued a career in paediatric endocrinology in Cambridge, UK with special interest in disorders of sexual differentiation. She relocated to the UAE in 2006 where she founded a tertiary Paediatric Endocrine Department.



SPEAKERS' BIOGRAPHY



Dr. Zulf Mughal

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



Professor M Zulf Mughal graduated in medicine from the University of Liverpool, UK, in 1978. He received postgraduate training in Paediatrics at hospitals in Manchester, Liverpool, in the UK and in Cincinnati, USA. He was appointed a Consultant Paediatrician in 1988. He was employed as a Consultant in Paediatric Bone Diseases at the Royal Manchester Children's Hospital. In October 2023, Prof Mughal took up the post of Consultant in Paediatric Bone Disorders at Al Jalila Children's Hospital, Dubai, UAE.

Professor Mughal has extensive experience in the management of childhood bone & mineral disorders. He has published >180 peer-reviewed scientific papers, invited reviews and book chapters. Professor Mughal was awarded the Charles Slemenda Award at the 7th International Conference on Children's Bone Health in Salzburg, Austria in June 2015 in recognition of his contribution to Paediatric Bone Research. In June 2021, Professor Mughal was awarded the Dent Award by the Bone Research Society.



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. Benjamin Cocanougher is a Medical Geneticist and Physician-Scientist in the Division of Human Genetics and an Assistant Professor in the UC Department of Pediatrics. He completed his fellowship in Medical Genetics and Genomics at Duke University Hospital in 2024 and postdoctoral training in Biochemistry in the laboratory of Robert Lefkowitz at Duke University. His clinical interests include neuromuscular disorders, neurodevelopmental disorders, and lysosomal storage disorders, while his research focuses on receptor biology and developing therapies for rare disorders.



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



Moeenaldeen AlSayed is a Consultant Clinical Geneticist in Clinical Biochemical Genetics and Metabolic Diseases at King Faisal Specialist Hospital & Research Centre in Riyadh, Saudi Arabia, and a Professor of Genetics at Alfaisal University. He is the Founder and Director of the MSc Genetic Counselling Programme at Alfaisal University, established in 2014, which has trained many of the practicing genetic counsellors in Saudi Arabia. Professor AlSayed previously served as Chair of the Department of Medical Genetics at King Faisal Specialist Hospital & Research Centre for 11 years, during which he established the institution's Adult Genetics & Metabolic Diseases, Cancer Genetics, and dedicated Genetic Counselling services. He obtained his MBBS from King Saud University, completed his pediatric residency at Yale-New Haven Children's Hospital and fellowships in Clinical Genetics and Clinical Biochemical Genetics at Baylor College of Medicine, and holds an MBA from the University of Tennessee, USA.



SPEAKERS' BIOGRAPHY



Dr. Hiba Alblooshi

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



Dr. Hiba Alblooshi is an Assistant Professor in the Department of Genetics and Genomics at the United Arab Emirates University (UAEU) and Director of the UAEU Genomics Laboratory. She holds a PhD in Medical and Forensic Sciences from the University of Western Australia and a Bachelor's degree in Genetics and Anatomy from the University of Melbourne.

Her research focuses on the genomic architecture and molecular mechanisms of rare and complex diseases, with particular emphasis on rare genetic disorders, autoimmune and neuropsychiatric conditions. Dr. Alblooshi integrates next-generation sequencing, multi-omics approaches, and computational genomics to identify disease-causing variants and characterize their functional impact. Her work aims to advance rare disease gene discovery, improve molecular diagnostics, and support the development of precision medicine approaches, particularly within the UAE population.



Dr. Heba Elabd

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



- Clinical Associate Professor of Clinical Genetics at Mohammed Bin Rashid University of Medicine and Health Sciences (MBRU)
- Assistant professor at Ain Shams University Faculty of Medicine Pediatric / Genetic Department
- Medical Genetic Consultant at Al Jalila Children's Hospital

Education:

- Medical Doctorate in Medical and Clinical Genetics. Ain Shams University
- Master of Science in Medical and clinical Genetics. Ain Shams University
- M.B.,B.Ch. Faculty of Medicine. Ain Shams University.
- Residency at Ain Shams University hospitals - Pediatric Department

SPEAKERS' BIOGRAPHY



Dr. Mehtab Iqbal
Consultant Pediatric Neurologist
Tawam Hospital, Al Ain, UAE



Dr. Chaudhry Muhammad Mehtab Iqbal is a Consultant Paediatric Neurologist, Division Chief & Head of Paediatric Neuromuscular Services at Tawam Hospital, Al Ain, UAE, with UK CCT training in Paediatric Neurology. His key clinical interest is paediatric neuromuscular disorders, particularly spinal muscular atrophy (SMA) and Duchenne muscular dystrophy (DMD).

He previously served as Clinical Lead for Neuromuscular Services at University Hospitals of Leicester, UK, where he was involved in developing neuromuscular services and establishing intrathecal nusinersen treatment for children with SMA.

He is also an experienced speaker at national and international scientific meetings, with particular expertise in SMA, DMD, and paediatric neuromuscular care.

FAMILY DAY SPEAKERS' BIOGRAPHY



Mr. Ahmed Zainoun
Founder and President
Son of Al Qamar Association,
Morocco
Winner of Hope Maker 2025



أحمد زينون، مؤسس ورئيس جمعية صوت القمر بالمغرب، يكرّس جهوده منذ ٢٠١٩ لحماية الأطفال المصابين بجفاف الجلد المصطبغ وتحسين جودة حياتهم، من خلال توفير وسائل الوقاية من الأشعة فوق البنفسجية، والرعاية الطبية والاجتماعية والنفسية. كما ساهم في تطوير قطاع حماية مغربي مبتكر والمشاركة في بحث جيني حول المرض يشمل ٥٠ طفلاً في المغرب. وفي سنة ٢٠٢٥، حصل على لقب «صانع الأمل» في الوطن العربي تقديراً لجهوده الإنسانية وتسلم التكريم من صاحب السمو الشيخ محمد بن راشد آل مكتوم حفظه الله في دبي.



Mrs. Sabha Al Shamsi
Zayed Higher Organization
for People of Determination,
UAE



A member of the UAE Rare Disease Society, a mother of a Rare Hero living with Moon Children Syndrome (Xeroderma Pigmentosum), and an advocate for raising awareness about rare diseases and People of Determination. Through her personal experience, she shares a powerful human message that reflects the realities of patients and their families, while advocating for stronger psychological and social support and greater community inclusion. She has transformed the challenges of her journey as a mother into a voice for awareness and a message of hope and empowerment for every family living with a rare disease.

FAMILY DAY SPEAKERS' BIOGRAPHY



Ms. Shamsa Almheiri

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



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



Ms. Eiman Jassim Al Ali is a UAE national and a Bachelor of Physiotherapy graduate with extensive experience in rehabilitation and support services for People of Determination. She worked at Dubai Hospital from 2010 to 2013 before joining the Ministry of Community Development, where she spent over a decade at the Dubai Rehabilitation Center for People of Determination. Since October 2024, she has been working with the Ministry's POD Card Department. Her experience includes supervising therapists, supporting the quality of POD card requests, developing personalized therapy plans, and coordinating multidisciplinary teams. She has expertise in early intervention, child development, cerebral palsy, Applied Behavioural Analysis, and equine therapy. She also contributes to staff development through training and annual professional development programs.



FAMILY DAY SPEAKERS' BIOGRAPHY



Mr. Khaled Al Abdouli

Director - Wahat Al-Rushd
Sharjah, UAE



Director - Wahat Al-Rushd
Sharjah, UAE



Dr. Fatima Ali Al Marzouqi

Social Expert
Department of Social Services,
Sharjah, UAE



د. فاطمة علي المرزوقي
خبير اجتماعي - مكتب الخبراء والاستشاريين
أثر الخدمات الاجتماعية بالشارقة

دكتورة في علم الاجتماع التطبيقي، تمتلك خبرة مهنية تفوق ١٥ عاماً في المجال الاجتماعي بإمارة الشارقة، وخبرة متخصصة في إدارة الحالات، وحماية الطفل، والإرشاد الأسري، والرعاية الاجتماعية والنفسية. وتدرجت خلال مسيرتها المهنية في عدد من المهام والمناصب الإشرافية والإدارية، شملت إدارة مراكز ودور الرعاية الاجتماعية والإشراف على فرق العمل، إلى جانب إعداد البرامج والمبادرات الاجتماعية والتوعوية وتنفيذها. وتتمتع بخبرة في التعامل مع قضايا الطفل والأسرة، وإدارة ومتابعة الحالات الاجتماعية، وتقديم الدعم النفسي والاجتماعي، إلى جانب تنظيم ورش العمل والندوات، وإعداد أوراق العمل والتقارير المهنية، والمشاركة في المبادرات والبرامج المرتبطة بالرعاية والحماية الاجتماعية. وكما أسهمت في تمثيل دولة الإمارات العربية المتحدة في عدد من الاجتماعات والبعثات الرسمية خارج الدولة ذات الصلة بالمجال الاجتماعي وحماية الطفل، والمشاركة في تبادل الخبرات والتجارب في المجالات ذات الصلة



Ms. Nehad Al Hemeiri

POD Department
Community Development
Authority Dubai, UAE



POD Department
Community Development
Authority Dubai, UAE



FAMILY DAY SPEAKERS' BIOGRAPHY



Mr. Rashed Bin Haider
Child Protection Department
Community Development Authority,
Dubai, UAE



أنا راشد بن حيدر، خريج تخصص علم النفس، وأكمل حالياً دراسة الماجستير في علم النفس الإكلينيكي. أعمل في هيئة تنمية المجتمع بحبي، ضمن إدارة حماية الطفل، كأخصائي حماية طفل.



Dr. Nazem Almanssour
People of Determination and
Senior Citizens Empowerment Expert
Ministry of Family



ناظم فوزي المنصور يحمل شهادة البكالوريوس في علم الإعاقة والتأهيل ودرجة الماجستير في أمراض اللغة والكلام، يعمل في وزارة الأسرة بمسمى وظيفي خبير مساعد لتمكين أصحاب الهمم وكبار المواطنين. باحث في مجال الإعاقة وله عدد كبير من الدراسات والأبحاث وله عدد من المؤلفات في مجال الإعاقة والتأهيل، محاضر في عدد من الجامعات المحلية والعربية.



Dr. Abdulla Al Hammami
Assistant Specialist - Visual Impairment;
Family and Educational Consultant
Emirates Schools Establishment (ESE), UAE



حاصل على شهادة الدكتوراه المهنية في الكونش الأسري، حاصل على شهادة الماجستير المهني في التوجيه والإرشاد، حاصل على درجة البكالوريوس التربوي قسم إعداد معلم مجال اللغة العربية والتربية الإسلامية، مجاز بسند متصل إلى النبي صلى الله عليه وسلم في ترتيب وتجويد القرآن الكريم برواية حفص عن عاصم، مدرب معتمد من البورد الأمريكي الكندي، أعمل حالياً اختصاصي إعاقة بصرية في وزارة التربية والتعليم منذ عام ٢٠١٧، افتتحت أكثر من ٢٠ فعالية على مستوى دولة الإمارات بقراءة القرآن الكريم، شاركت في تقديم أكثر من ٢٥٠ ورشة وفكرة ومحاضرة في مختلف المجالات التربوية، شاركت في تنظيم الفعاليات والمبادرات المجتمعية مع جهات محلية مختلفة، قدمت أكثر من ١٥ احتفالا وأدريت أكثر من ١٠ ندوات وجلسات حوارية، تطوعت مع جهات حكومية وخاصة مختلفة في عدة جوانب، لدي ما يقارب من ٢٠ دبلوم معتمد في مجال الصحة النفسية والتدريب والإرشاد الأسري، حضرت أكثر من ٢٥ دورة تدريبية حول الإرشاد الأسري والصحة النفسية والقيادة والمسؤولية وإدارة الحوارات والتعامل مع برامج الحاسوب المختلفة، قدمت أكثر من ١٥٠ ورشة ومحاضرة ودورة تدريبية وندوة حول مجال الإعاقة البصرية وآلية تدريسها وتدريبها على مختلف المهارات الرقمية والتعامل مع هذه الفئة على مستوى الوطن العربي، قدمت أكثر من ٧٠ محاضرة حول التدريب المهني والتنمية البشرية، إجمالي من حضر المحاضرات والورش والدورات التي أقدمتها ما لا يقل عن ١٠٠٠ شخص واقعيا وافتراضيا عبر الإنترنت، حاصل على جائزة بصيرة العالمية كأحد الرواد المؤثرين المكفوفين على مستوى الوطن العربي، حاصل على جائزة الجوهرة كشخصية استثنائية خدمت مجال التعليم ضمن جائزة الشارقة للتميز التربوي، كتبت كتابي الأول بعنوان: الكتابة بالقلم الأبيض وتم نشره نصياً وصوتياً على نطاق واسع، استضافتني عدة قنوات وإذاعات محلية وعربية، كتبت أكثر من ٥٠ مقال وخاطرة على مواقع التواصل الاجتماعي، أدير قناة خاصة بي على يوتيوب أقوم من خلالها بنشر الموضوعات الهادفة وأناقش المتابعين فيها، كما أدير مجتمعاً خاصاً بي عبر واتساب، أنشر من خلاله ما يمكن مناقشته كتابياً مع الجمهور، وما يتعلق بي من أخبار وأحداث وفعاليات مستجدة



FAMILY DAY SPEAKERS' BIOGRAPHY



Dr. Fatema AlHayyas
Family Guide - Dubai Courts


Family Guide - Dubai Courts



H.E. Dr. Eman AlHashmi
Founder and Chairperson
Autoimmune Association, UAE


المؤسس ورئيس مجلس إدارة جمعية المناعة الذاتية (الأولى والوحيدة من نوعها وشموليتها على مستوى العالم)، وهي أول ملحنة إماراتية، وأول موزعة موسيقية، وأول مؤلفة متخصصة في الأوركسترا والموسيقى التصويرية، عازفة بيانو، رسامة، كاتبة وشاعرة وسيناريست، حاصلة على شهادة دولية من منظمة WIPO في حقوق الملكية الفكرية، وهي مدربة تطوير ذات معتمدة دولياً، وحاصلة على دبلومه معتمد كمقيم لمنظومة التميز الحكومي، ودبلومه مهني في تمكين المرأة وتأهيلها إلى المراكز القيادية، ودبلومه تدريبي في الاستشارات النفسية، ودبلومه تدريبي في الشراكة المجتمعية وأيضاً لرعاية المرضى، وكذلك دبلومه تدريبي في الشُّعر، وشهادة احترافية في الإنتاج الموسيقي كقادة في صناعة الموسيقى العالمية من جامعة بيركلي، وشهادة البكالوريوس في إدارة الموارد البشرية، وماجستير الآداب في فنون الاتصال والعلاقات العامة الاستراتيجية، والدكتوراه في إدارة الأعمال تخصص إدارة المشاريع، و(جميعهم بتقدير امتياز مع مرتبة الشرف)، كما نشرت بنجاح ٦ كتب إلى الآن، ولديها العديد من الإنجازات المحلية والدولية، وأكثر من ٥٥ مشاركة كانت الأولى من نوعها في الإمارات.



Ms. Gabrielle Rosario
Product Manager, AI Office,
PureHealth, UAE


Gabrielle Rosario is a product manager in the AI Office at PureHealth, where she works on artificial intelligence applied to clinical care, including the detection of rare disease. She has more than sixteen years across healthcare, life sciences and technology, with previous roles at Philips, Deloitte and Abcam. She writes One in a Million, a publication on artificial intelligence in rare disease diagnosis, therapeutics and access. She speaks from both sides of the consultation room, as someone who builds these tools professionally and uses them as a patient.



FAMILY DAY SPEAKERS' BIOGRAPHY



Dr. Fida Diyaab

Founder of TAPY, and an advocate dedicated to supporting mothers of People of Determination and families affected by rare diseases.



Founder of TAPY, and an advocate dedicated to supporting mothers of People of Determination and families affected by rare diseases.

الدكتورة فداء دياب
مؤسس. شركة. تابي
ناشطة في مجال دعم امهات اصحاب الهمم والأمراض النادرة



POSTER PRESENTERS

- 1 **Comprehensive Newborn Screening of Lysosomal Diseases: Insights from the LysoNeo Study**
Prof. Abdellah Tebani, Professor / Clinical Academic Consultant, Rouen University Hospital / Metabolic Biochemistry Department
- 2 **Myxedema Coma in Neuronal Ceroid Lipofuscinosis Type 6: a life-threatening complication in a rare disease**
Mr. Ans Ahmed Mahmood, Medical Student, Gulf Medical University
- 3 **Multisystem Inflammatory Syndrome in Neonates (MIS-N): A Case Report and Clinical Insights**
Mr. Yasser Abd Alsamad, Medical Student, University of Sharjah
- 4 **Variant-Specific Proteostasis Defects Define Pathogenic Mechanisms in Rare TGFBR2-Associated Aortopathies**
Ms. Fadia Mahmoud Aayed Abu Sailik, PhD student, UAE University
- 5 **Hematological Manifestations and Platelet Abnormalities in Pediatric DiGeorge Syndrome: A Retrospective Study on Thrombocytopenia and GPIIB Association**
Ms. Dana Haj Mohammed (1), Student, University of Sharjah
- 6 **The Enigma of West Syndrome: A Case of Infantile Spasms Without Genetic Clues**
Dr. Ali Raafat Ammar, Physician, Faculty of Medicine, Ras Al Khaimah Medical and Health Science University
- 7 **Elucidating the Cellular and Molecular Mechanisms of Discoidin Domain Receptor 2 (DDR2) Disease-Causing Mutations**
Mrs. Anjana Raj, PhD Student, United Arab Emirates University
- 8 **Kaposi's Sarcoma in Patients Exposed to Calcineurin Inhibitors or Systemic Corticosteroids: A Two- Decade Real-World Safety Assessment.**
Dr. Sara Omar Abu Aleenein, Medical Student, Jordan University of Science and Technology, Medicine
- 9 **ExomePilot: An Interactive AI-Ready Platform for Streamlined Rare Disease Genomic Diagnostics**
Dr. Nour al dain Marzouka, Assistant Professor, Department of Genetics & Genomics, College of Medicine and Health Sciences, United Arab Emirates University, Al Ain, United Arab Emirates
- 10 **Severe Neonatal Nemaline Myopathy Associated with NEB Gene Mutation: A Case Report**
Dr. Aaisha Mohammed Rafi (1) Medical Resident, Aster Hospital Dubai
- 11 **Fanconi-Bickel syndrome presenting with neonatal hyperglycemia: A case report**
Dr. Aaisha Mohammed Rafi (2) Medical Resident, Aster Hospital Dubai
- 12 **FNAIT in the Middle East: A Confirmed Case Highlighting Immunogenetic Diversity and Evidence-Based Neonatal Management.**
Dr. Hamza Haj Mohamad, Pediatric resident, AL Jalila Hospital
- 13 **Clinical and Genetic Evaluation of Childhood-Onset Epilepsy: A Comprehensive Analysis**
Dr. Alfiya Fasaludeen, Post doctoral researcher, Department of Genetics and Genomics, College of Medicine and Health Sciences, United Arab Emirates University, Al Ain, United Arab Emirates
- 14 **Surgical Management of Hemimegalencephaly: A Systematic Review and Meta-Analysis of Seizure Freedom and Complications**
Ms. Shriya Karlapudi Year 3 Medical Student, Faculty of Life Sciences and Medicine, King's College London, UK
- 15 **Combined Endoscopic Submucosal Dissection and Complete Endoscopic Hand Suturing for Solitary Rectal Ulcer Syndrome: A Novel Global Case Report**
Dr. Shahd Faris Alqudah, MBBS, University of Sharjah
- 16 **Paramyotonia Congenita in an Adolescent With SCN4A Mutation: The Importance of Clinical Phenotyping & Early Genomic Testing**
Dr. Aisha Sajjad (1), Medical Intern, Kings College Hospital



POSTER PRESENTERS

- 17 **Cholestatic Hepatitis in Pediatric Stevens–Johnson Syndrome/Toxic Epidermal Necrolysis: A Diagnostic Challenge**
Dr. Aisha Sajjad (2), Medical Intern, Kings College Hospital
- 18 **Late Onset Glutaric Aciduria Type II: Case Report and Literature Review**
Dr. Mohammed Naji AlAbsi, Medical Intern, Sheikh Khalifa Medical City
- 19 **A Novel Loss-of-Function variant in TNS2 provides further evidence for TNS2-related nephrotic syndrome**
Ms. Sara Alhmoudi, Medical Research Specialist, UAE University
- 20 **Diagnostic Odyssey – What Comes After Negative Genome?**
Dr. Aya Abuelhajja, Clinical Genetics Physician, Boston Children's Hospital, Harvard Medical School
- 21 **Neurodevelopmental Disorder Associated with Heterozygous HNRNPD Variant in an 8-Year-Old Boy: A Case Report**
Dr. Zahra Mohamed Yusef Majichian, Pediatric resident, 1 Pediatric Residency program, Sheikh Khalifa Medical City, Abu Dhabi
- 22 **Coexisting Persistent Hyperinsulinemic Hypoglycemia of Infancy and epileptic encephalopathy: A Diagnostic Challenge in an Infant with Refractory Seizures**
Dr. Maitha Abdulla Mohammed Alhay Alshamsi, Medical Intern, Sheikh Shakhboud Medical City (SSMC)
- 23 **Where Rare Cancer Diagnostics Fail: A Comparative Analysis of Biomarker Testing Vulnerabilities**
Ms. Nooran Sabati, BSc. Medical Laboratory Sciences Student, Abu Dhabi University
- 24 **Population Representation and Enrichment of Pathogenic ATP7B Variants in Middle Eastern Populations**
Dr. Fahd Tayyab, BSc Student in Biomolecular and Medical Genetics (Undergraduate Researcher), Biomedical Sciences Department, College of Health Sciences, Abu Dhabi University, Al Ain, UAE
- 25 **Analysis of Whole Exome Sequencing Data for the Diagnosis of Prenatal Disease Variants in a UAE Cohort**
Ms. Lana Mashal, Student, Abu Dhabi University
- 26 **Reversing Acute Cardiomyopathy With Coenzyme Q10 Supplementation in Cobalamin B Disease: A Case Report and Literature Review**
Dr. Dalia Ra'a Said (1), Clinical Genetics Fellow, Tawam Hospital
- 27 **Hereditary Spastic Paraplegia: A 15-Year Retrospective Cohort Study of Clinical and Genetic Findings from Tawam Hospital, UAE**
Dr. Dalia Ra'a Said (2), Genetics Fellow, Tawam Hospital-SEHA
- 28 **When Neutropenia Unmasks DADA2: A Rare Intronic ADA2 Variant Identified by Whole-Exome Sequencing in an Infant: A Case Study**
Dr. Nadia Salaheldin Hamid Elsayedelfeil, Pediatric Resident, Al Qassimi Women's and Children's Hospital
- 29 **Primary immunodeficiency disorders in consanguineous populations: Diagnostic Challenges and Outcomes**
Aarifa Banu, Doctor, Tbilisi State Medical University, American Programme, Tbilisi, Georgia
- 30 **Multisystem Cardiovascular Complications and Therapeutic Challenges in a Patient with Marfan Syndrome**
Dr. Mustafa Elsheikh Farah Mohamed Elhassan (1), Medical Intern, Fakeeh University Hospital
- 31 **UAE–GCC–Global AI-Enabled Rare Disease Registry: A Transformative Platform for Precision Medicine and Societal Impact**
Advisor Mohamad Ahmd Layla, Chief Operations Officer for Global Alliance for Artificial Intelligence (GAFAI), Global Alliance for Artificial Intelligence (GAFAI)
- 32 **When Hypocalcemia Hides: Atypical Symptomatic Hypocalcemia in an Adult with DiGeorge Syndrome**
Dr. Doaa Elsheikh Farah Mohamed Elhassan (1), Internal Medicine Resident, Dubai Health
- 33 **The role of antenatal ultrasound in early detection of alobar holoprosencephaly**
Dr. Mariam Elsayed Mohamed (1), Intern physician, Fujairah hospital, EHS, Fujairah hospital, EHS



POSTER PRESENTERS

- 34 **MT-ND5–Associated Mitochondrial Disease Presenting with Multisystem Neurological and Ophthalmologic Manifestations in a Pediatric Patient: A Case Report**
Dr. Doaa Elsheikh Farah Mohamed Elhassan (2), Internal Medicine Resident, Dubai Health
- 35 **Joubert Syndrome (JS) with Intellectual Disability in a 28-Year-Old - The First Documented Case in the UAE**
Dr. Prof. Madhusudan Deepak Thalitaya, Consultant Psychiatrist and Head of Department, Intellectual Disability Psychiatry, Professor of Psychiatry, GMU and MBRU, EHS, Al Amal Psychiatric Hospital, Dubai, UAE
- 36 **Beyond Binary: Frequency-based Symptoms for Fabry Disease Detection using Machine Learning Algorithms**
Dr. Muhammad Jalal Khan, Postdoctoral Fellow, United Arab Emirates University
- 37 **Spontaneous Hemothorax Secondary to Hereditary Multiple Exostosis: A Rare Complication Masquerading as Pulmonary Tuberculosis**
Mr. Abdulrahman Abbas Yusuf Mohammed, General Medical Practitioner, Port Sudan Teaching Hospital
- 38 **Integrative Genomic and Pathway Analysis of Inherited Ocular Diseases Reveals Anatomical and Molecular Signatures Across the Eye**
Waruni Nawagamuwa, PhD Scholar, Department of Genetics and Genomics- UAE University
- 39 **Resolving Diagnostic Pitfalls in Inherited Ocular Disease Using Long-Read Sequencing and Integrated Genomic Analysis in an Emirati Cohort**
Department of Genetics and Genomics, College of Medicine and Health Sciences, United Arab Emirates University, Al-Ain, United Arab Emirates
- 40 **Three-Arm Phenotype: Neurodevelopmental, Autoinflammatory, and Immunodeficiency Features From 6q27 Deletion**
Dr. Rana Haitham Salman, Pediatrician, Al Qassimi Women and Children's Hospital
- 41 **Uncharted Territory: Defining the Clinical, Radiologic, and Genetic Landscape of Pediatric Congenital Brain Malformations in the UAE**
Dr. Faizah Hashimy (1), Specialist fellow, Tawam Hospital
- 42 **Efficacy of Hydroxychloroquine in Managing Respiratory Complications in Niemann-Pick Disease Type C**
Dr. Faizah Hashimy (2), Specialist fellow, Tawam Hospital
- 43 **Emanuel Syndrome: A Physiotherapy Overview**
Ms. Shahwar Fatima Ansari, Master Student, Institute of Public Health, College of Medicine and Health Sciences, United Arab Emirates University, Al Ain, United Arab Emirates
- 44 **Beyond Common Arrhythmias: Discovering Brugada Syndrome in a Patient With Nonspecific Symptoms**
Dr. Noel George Cherian (2), Medical Intern, Thumbay University Hospital
- 45 **Peri induction Cardiovascular Collapse and Delayed Respiratory Failure in MPS I: Anesthetic Challenges and Successful Epidural Analgesia Despite Severe Scoliosis**
Dr. Thoayba Gaafer Mahgoub Elhassan, PHYSICIAN / SPECIALIST, Al Qassimi Woman Children Hospital
- 46 **A retrospective cross-sectional study on newborn screening and prevalence of disorders among UAE population**
Ms. Khadija Shafique, Genetic Counselor, United Arab Emirates University, Department of genetic and genomics, College of Medicine and Health Sciences
- 47 **a. Dual Chromosomal Imbalance from Familial t(15;20): A Neonatal Case of Monosomy 15q and Trisomy 20q with Severe Multisystem Involvement**
b. Unbalanced translocation with monosomy 15q26.2–qter and trisomy 20q12–qter in a late preterm neonate born to a familial balanced t(15;20): expanding the genotype–phenotype spectrum"
Dr. Sukena Susnerwala, Specialist, Latifa Hospital
- 48 **Refractory cyclic vomiting syndrome in TUBB3 R262H syndrome: a case report**
Dr. Rosul Adel Makkiyah, Pediatrics resident doctor, Al Jalila Children's Speciality Hospital



POSTER PRESENTERS

- 49 **Paired-Like Homeobox 2B (PHOX2B) Mutation and the Hidden Endocrine Puzzle: Hyperinsulinism in Congenital Central Hypoventilation Syndrome**
Dr. Mohamad Sabsabee (1), Pediatric resident, Al Jalial children's Speciality Hospital
- 50 **When One Gland Speaks First: Autoimmune Polyendocrinopathy Syndrome Type 1 (APS-1) Unmasked by Isolated Hypoparathyroidism**
Dr. Mohamad Sabsabee (2), Pediatric resident, Al Jalial children's Speciality Hospital
- 51 **Follistatin as a Potential Biomarker for diabetes in patients with β -thalassemia major: A Cross-Sectional Study**
Dr. Alaa Al Hajji, Medical tutor, University of Sharjah, University of Sharjah
- 52 **Multidisciplinary Management of Severe Hidradenitis Suppurativa in a Specialized Wound Care Service: A Clinical Case Report**
Ms. Aisha Mostafa Hassan (2), Charge nurse/wound management, SKHF hospital
- 53 **Retrospective Study of Clinical and Genetic Profiles of Alpha-Mannosidosis Patients From the UAE**
Mr. Ali Kassem Saad, PhD Student, UAEU
- 54 **A case of report late-onset biotinidase deficiency presenting as neuromyelitis optica spectrum disorder**
Ms. Anna Chudaikina, Clinical Geneticist, Morozov Children's City Clinical Hospital
- 55 **Knowledge, Attitudes, and Perceptions to the Genome Program: A Cross-Sectional Study of UAE Adults**
Dr. Reem Mohamed Alabsi, 4th year medical student, College of Medicine - University of Sharjah
- 56 **Perioperative Management of a Patient with MELAS Syndrome and Hypertrophic Cardiomyopathy Undergoing Ureteroscopic Stone Removal Under Spinal Anaesthesia: A Rare Case Report**
Dr. Shirang Nagorao Bamne, Consultant Critical Care Medicine, Nmc Specialty Hospital, Abu Dhabi
- 57 **Assessing the Current Public Knowledge, Attitudes, and Perceptions Regarding Consanguineous Marriages in the United Arab Emirates**
Dr. Shahd Alali, Medical school graduate, University of Sharjah
- 58 **Beyond a Single Diagnosis: A Child with Coexisting DiGeorge Syndrome and Ataxia-Telangiectasia**
Dr. Sara Mohamed Ali, Department of Pediatrics, Sheikh Shakhbout Medical City (SSMC), Abu Dhabi, United Arab Emirates, Sheikh Shakhbout Medical City (SSMC)
- 59 **From short-read genome sequencing to targeted treatments for rare diseases through the CincyKidsSeq study**
Dr. Anne Slavotinek Professor and Division Director, Human Genetics, Cincinnati Children's Hospital Medical Center, Cincinnati, OH
- 60 **a. Congenital Harlequin Ichthyosis: A Case Report**
Dr. Jini Kottuvala Narayanan, Specialist Pediatrics, LLH Hospital Abu Dhabi, Burjeel holdings
- 61 **Dual Molecular Diagnosis of Late-Onset Leigh Disease and Nephronophthisis Type 3 in an Emirati Woman**
Dr. Fatima AlKindi, Internal Medicine, Sheikh Tahnoon Bin Mohammed Medical City and Tawam Hospital SEHA, PureHealth, Al Ain, UAE"
- 62 **Genetic Molecular background of Prolonged QT syndrome in patients of Al Ain region diagnosed in the years between 2014 and 2024**
Dr. Waed Sumairi, Fellow, Tawam hospital
- 63 **The Role of Pirfenidone in Parkinson's Disease: Mechanisms and Therapeutic Potential**
Ms. Mouza Ali Hasan AlQaishi Alshehhi, PhD student, UAEU collage of medicine
- 64 **Treatment of Reactivation and Progression in Langerhans Cell Histiocytosis (LCH): A 17-Year Single Center Experience from Tertiary Care Hospital in Pakistan**
Dr. Muhammad Rafie Raza, Consultant, Indus Hospital & Health Network, Karachi (IHHN)



POSTER PRESENTERS

- 65 **X-Linked Agammaglobulinemia Masquerading as Hyper-IgE Syndrome: An Unusual Diagnostic Challenge**
Dr. Aysha Dilsha Mullakkantakath, Junior Resident Doctor, Department of Pediatrics, Lady Hardinge Medical College and Kalawati Saran Children's Hospital, New Delhi, India
- 66 **Beyond Malnutrition: A Rare Diagnosis of 5,10-Methenyltetrahydrofolate Synthetase Deficiency in a Child Presenting With Severe Acute Malnutrition and Global Developmental Delay**
Dr. Brenda Syngkon (1), Junior Resident, Department of Paediatrics Lady Hardinge Medical College And Kalawati Saran Children's Hospital, New Delhi, India
- 67 **Unmasking Fanconi Anemia: A Three-Case Series of Clinical Clues and Molecular Diagnosis**
Dr. Brenda Syngkon (2), Junior Resident, Department of Paediatrics Lady Hardinge Medical College And Kalawati Saran Children's Hospital, New Delhi, India
- 68 **Mapping the PAH Variant Landscape in Phenylketonuria Across the Middle East and North Africa: A Systematic Review**
Dr. Nusrat Ferdouse Primary Care Physician, Master's Candidate in Genomic Medicine, UAE university, Al Ain, UAE
- 69 **Beyond Ocular Disease: Severe Neurodevelopmental Impairment and Neurodegeneration in SIX6-Related Disorder**
Dr. Sana Al-Rawi, Pediatric Specialist, NMC Royal Hospital
- 70 **Prevalence and Characteristics of Factor VIII Inhibitors in Children with Hemophilia A: First National Data from Uzbekistan**
Dr. Dilorom S. Makhmudova, Scientific Secretary, Scientific and Practical Medical Center of Pediatric Oncology, Hematology and Immunology and International Academic Hub for Childhood Cancer, Scientific and Practical Medical Center of Pediatric Oncology, Hematology and Immunology, Tashkent, Uzbekistan
- 71 **The Other Side of CAMT: Unveiling an Exceptionally Rare THPO Mutation**
Dr. Tanisha Negi, Senior Resident, Department of Paediatrics, Kalawati Saran Children's Hospital, LHMC, New Delhi, Department of Paediatrics, Kalawati Saran Children's Hospital, LHMC, New Delhi
- 72 **Transparent Phenotype-Driven Variant Re-Analysis for Unsolved Rare Disease Cases in a Middle Eastern Cohort**
Ms. Fathimath Nubla Latheef, Department of Cancer and Genomic Sciences, University of Birmingham Dubai, Dubai, UAE
- 73 **Diagnostic Delay and Its Determinants in Rare Neuropsychiatric Genetic Disorders in the UAE: A Comparative Analysis with International Literature**
Ms. Fatima Ahmad, B.sc. Molecular and Medical Genetics student, Abu Dhabi University
- 74 **Perioperative outcomes in pediatric hemophilia A on emicizumab prophylaxis: a systematic review and meta-analysis**
Ms. Noor Ismail Abu Tobeh (2), Medical student, University of Sharjah
- 75 **Teaching Machines to Spot Zebras: AI-Assisted Diagnosis in Rare Disease**
Mr. Syed Aasim Syed Nasir (2), 6th Year Medical Student, Faculty of Medicine, Tbilisi State Medical University, Tbilisi, Georgia
- 76 **Successful treatment of genetically proven neonatal diabetes mellitus (NDM): case series from the UAE**
Dr. Juman Babi, Resident Pediatrics, SEHA-SSMC
- 77 **Gamifying Public Health Genomics Education: Development and Pilot Evaluation of the Jackaroo Game for Students and Healthcare Professionals**
Dr. Azhar Talal Rahma, Instructor at the Institute of Public Health, College of Medicine and Health Sciences, UAE



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