MENA Congress for RARE DISEASES 2025

17-20 April 2025, Beach Rotana Hotel, Abu Dhabi, UAE

IN PARTNERSHIP WITH BMC BURJEEL MEDICAL CITY

By Burjeel Holdings

The largest event for rare diseases in the region:

- 4 full days
- CME hours (under process)
- 50+ sessions
- 160+ speakers (including 70+ international experts)
- 1200+ expected attendance

Managed By:

PEARL EVENT MANAGEMENT SERVICES

MENA Congress for RARE DISEASES 2025
17-20 April 2025, Beach Rotana Hotel, Abu Dhabi, UAE
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Welcome Letter

Prof. Ayman El-Hattab

Congress President, MENA Congress for Rare Diseases 2025
Professor, College of Medicine, University of Sharjah, Sharjah
Consultant Clinical Genetics at Burjeel Medical City, University Hospital Sharjah, Kanad Hospital, and Genesis Healthcare Center, UAE

The **MENA Congress for Rare Diseases 2025 in partnership with Burjeel Medical City** will take place from 17 to 20 April 2025 at Beach Rotana Hotel, Abu Dhabi, United Arab Emirates.

The **previous MENA Congress for Rare Diseases 2024** held on 16-19 May 2024 in Abu Dhabi, turned out to be the largest event for rare diseases and a key milestone in showcasing the regions dedication to improving the lives of individuals afflicted with these disorders. It was attended by **1105 delegates with 17% coming from 47 countries outside the UAE**. The meeting was held over 4 full days and consisted of 39 sessions including 139 presentations given by **141 speakers, including 51 international experts coming from 27 different countries**. The presentations received very high evaluations as the vast majority of the attendees **(96.7%) scored the presentations as above average**. The congress also received 78 high-quality scientific abstracts related to different aspects of rare diseases. The abstracts were featured as oral presentations and posters and published in the PubMed Central-indexed scientific journal Therapeutic Advances in Rare Disease. **The top 7 abstracts were awarded and assigned oral presentations**. The congress was held under the patronage of H.E. Sheikh Nahayan Mabarak Al Nahyan who attended the opening ceremony and gave the opening speech. The congress received the support of **34 scientific partners** including UAE University, Abu Dhabi University, Ajman University, Rare Disease International, and Undiagnosed Disease International. The congress also received marketing support from 23 media partners including Balsam, Medarabia, and Rare Evolution Magazine; and was covered by key media and news outlets during and after the meeting including **WAM** (https://wam.ae/en/article/b36k5bz), Aletihad, and Albayan.

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Welcome Letter

Our upcoming meeting, **MENA Congress for Rare Diseases 2025 in partnership with Burjeel Medical City**, Beach Rotana Abu Dhabi, 17-20 April 2025, will continue to be the largest event for rare diseases in the region. It will last for 4 full days with more than 150 speakers including more than 70 international speakers with expertise on various topics related to rare diseases. More than 1500 attendees are expected to participate with more than 25% coming from outside the country.

Again, the upcoming congress will accept scientific abstracts that will be presented as posters and will be published in a scientific PubMed Central-indexed journal. The top abstracts will be awarded and presented as oral presentations. Furthermore, the **Award for Outstanding Achievement in Rare Diseases** will be launched during the meeting and honored to pioneers in the field of rare diseases including researchers, healthcare providers, advocates, patients and their caretakers, and institutions. This award will be distributed during the opening ceremony of the congress.

The meeting will be promoted through our active social media platforms, email blasts to more than **250,000 healthcare providers in our databases**, and advertisements through more than **100 media and scientific partners**.

This conference is a unique platform that brings all stakeholders involved in rare diseases to one place to obtain the most updated knowledge, exchange experience, advance research, establish networks, and explore new horizons and collaborative opportunities aiming ultimately to provide better care for individuals with rare diseases.

We look forward to seeing you among us at the MENA Congress for Rare Diseases 2025 in partnership with Burjeel Medical City.

Ayman

Prof. Ayman El-Hattab
Congress President

Topic Covered

- Novel therapies for rare diseases
- Updates on diagnostics for rare diseases
- Artificial intelligence and rare diseases
- Research and innovation in rare diseases
- Gene and cell therapy
- Genetic counseling
- Hemoglobinopathies
- Rare ophthalmologic disorders
- Rare malignancies
- Rare immune diseases
- Angelman syndrome
- Huntington disease
- Duchenne muscular dystrophy
- Limb girdle muscular dystrophies
- Autism and neurodivergence
- Genomics and rare diseases
- Metagenomics in rare diseases
- Newborn screening
- Best practices for management of rare diseases
- Dental care for rare diseases
- Rehabilitation for rare diseases
- Nutritional support for rare diseases
- Pharmacoeconomics
- Access to orphan drugs for rare diseases
- Inclusion and diversity
- Patient advocacy for rare diseases
- Psychosocial challenges in rare diseases
- Media awareness and rare diseases
- Insurance coverage for rare diseases
- Challenging cases in rare diseases
- Patients' experiences and insights
- Compassionate healthcare

Participants

Medical doctors from variable specialties and dentists

Nurses, dietitians, therapists, and genetic counselors

Pharmacists and laboratory personnel

Medical and medical sciences students

Individuals with rare diseases and their families

Researchers, scientists, and educators

Laboratories and pharmaceutical companies

Clinics and hospitals

Academic institutions

Community services

Support and advocacy groups

Commitee

Congress President

Prof. Ayman El-Hattab
Congress President, MENA Congress for Rare Diseases
Professor, College of Medicine, University of Sharjah, Sharjah
Consultant Clinical Genetics at Burjeel Medical City, University Hospital Sharjah, Kanad Hospital, and Genesis Healthcare Center, UAE

Head of Scientific Committee

Prof. Khaled Musallam
Group Chief Research Officer, Burjeel Holdings, Abu Dhabi
Adj Professor, Khalifa University, Abu Dhabi, UAE
Adj Professor, Weill Cornell Medicine, New York, USA

Scientific Committee

Dr. Anwar Baban
Consultant Clinical Genetics and Genomics, Rare Diseases and Medical Genetics Units, Bambino Gesu Children's Hospital & Research Institute, Rome, Italy

Prof. Brahim Tabarki Melaiki
Consultant Pediatric Neurology, Prince Sultan Military Medical City, Riyadh, Saudi Arabia
Adjunct Professor Pediatric Neurology, AlFaisal University, Riyadh, Saudi Arabia

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

Prof. Maha Zaki
Professor, Clinical Genetics Department,
Human Genetics & Genome Research Institute, National Research Centre
Professor, Genetics Department, Armed Forces College of Medicine,
Cairo, Egypt

Commitee

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Prof. Tawfeg Ben-Omran
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Senior Consultant, Medical Genetic Department, Hamad Medical Corporation
Professor, Weill Cornell Medical College, Doha, Qatar

Prof. Uğur Özbek
Chair, RAREBOOST Project Director, Rare and Undiagnosed Disease Platform
Orphanet Country Coordinator, Izmir BioMedicine and Genome Center, Izmir, Turkey

Dr. Zahra Alsahlawi
Consultant Pediatric Inborn Errors of Metabolism and Clinical Genetics and Deputy Chief of Medical Staff, Salmaniya Medical Complex, Ministry of Health
Assistant Professor, Pediatric Department, Arabian Gulf University, Manama, Bahrain

Prof. Zuhair Al-Hassnan
Consultant, Department of Medical Genomics, Centre for Genomic Medicine, King Faisal Specialist Hospital and Research Center
Professor of Genetics, College of Medicine, Alfaisal University, Riyadh, Saudi Arabia

Session and Symposium Chairpersons

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Mrs. Areen Abuhejleh
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Professor, College of Medicine, Gulf University, Ajman, UAE

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Director, Help Center for the Middle East and North Africa, Kuwait, Kuwait

Prof. Bassam Ali
Professor in Molecular & Genetic Medicine and Leader of the Genetics & Development Research Priority Group, College of Medicine and Health Sciences, United Arab Emirates University, Al Ain, UAE

Dr. Binu George
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Mrs. Hanaa El-Sadat
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Clinical Professor, College of Health Sciences, Qatar University
Professor Adjunct, College of Health & Life Sciences, Hamad Bin Khalifa University, Doha, Qatar

Mrs. Rana Abu Khadra
Business Excellence Consultant, Co-founder of CureSCG, and Mother of Child with Limb Girdle Muscular Dystrophy, Abu Dhabi, UAE

Prof. Rasheed Alhammadi
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Session and Symposium Chairpersons

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Executive Director, Access for All - Institute for Accessibility and Inclusion, Abu Dhabi, UAE

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Founder and Owner of Anzyz Technologies AS, Kristiansand, Norway

Ms. Tanuka Gupta
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Dr. Zeinab Alloub
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Assistant Professor, Mohammed Bin Rashid University of Medicine and Health Sciences, Dubai, UAE

International Speakers

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Dr. Afaf Alsagheir
Head of Pediatric Endocrinology/Diabetes, King Faisal Specialist Hospital & Research Centre, Riyadh, Saudi Arabia

Ms. Alexandra Heumber Perry
Chief Executive Officer, Rare Diseases International, Geneva, Switzerland

Prof. Ali Taher
Associate VP for Academic Centers, Development, and External Affairs, Director for Naef K. Basile Cancer Institute, Professor of Internal Medicine - Hematology Oncology, and Founding Director of Fellowship and Residents Research Program, Faculty of Medicine, American University of Beirut, Beirut, Lebanon

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Mrs. Asmaa Al-Ismailia
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International Speakers

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Lecturer, University of Doha for Science and Technology and PhD Candidate, Hamad Bin Khalifa University and Sidra Medicine, Doha, Qatar

Dr. Bahaa Jalal
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Adjunct Professor Pediatric Neurology, AlFaisal University, Riyadh, Saudi Arabia

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Mrs. Duaa AbuRizik
CEO of Life and Health Insurance in Gulf Insurance Group and Foster Mother of Child with Developmental Delay and a Genetic Mutation in PRRT2 Gene, Kuwait

Dr. Elena Zhekaite
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International Speakers

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Ms. Khalsa Al-Kharusi
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Dr. Michael Kiefer
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International Speakers

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International Speakers

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Senior Consultant, Medical Genetic Department, Hamad Medical Corporation
Professor, Weill Cornell Medical College, Doha, Qatar

International Speakers

Prof. Uğur Özbek
Chair, RAREBOOST Project Director, Rare and Undiagnosed Disease Platform Orphanet Country Coordinator, Izmir BioMedicine and Genome Center, Izmir, Turkey

Dr. Valerie Jacquemin
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Assistant Professor, Pediatric Department, Arabian Gulf University, Manama, Bahrain

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Professor of Genetics, College of Medicine, Alfaisal University, Riyadh, Saudi Arabia

UAE-Based Speakers

Mr. Abdulla Lutfi
Autistic Savant Artist, Dubai, UAE

Dr. Abeer Al Naqbi
Consultant Family Medicine, Bateen Health Care Center, SEHA, Abu Dhabi, UAE

Dr. Adel Al Assy
Senior Manager, Pharmaceuticals, M42, Abu Dhabi, UAE

Mr. Alan Taylor
Certified Genetic Counselor, Al Jalila Children's Specialty Hospital, Dubai, UAE

Dr. Alberto Peralta
Assistant Professor in the College of Business and Former Director of Innovation, Abu Dhabi University, Abu Dhabi, UAE

Ms. Amina Maliki
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Mrs. Annie Kapinda
Diploma in Early Childhood Education, Founder of Anastasia Creation Handwork, and Mother of Child with Aicardi Syndrome, Dubai, UAE

UAE-Based Speakers

Mrs. Areen Abuhejleh
Head of Health Programs, Special Olympics UAE, Abu Dhabi, UAE

Dr. Arif A. Khan
Founder & CEO, Neuropedia Children's Neuroscience Center
Consultant Pediatric Neurologist
Associate Professor, Mohammed Bin Rashid University of Medicine and Health Sciences, Dubai, UAE

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Professor, College of Medicine, Gulf University, Ajman, UAE

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Founder and CEO, Balsam Healthcare Development, Dubai, UAE

Dr. Binu George
Consultant Neurodevelopmental Disabilities and Manager Special Needs, Sakina for Children, Abu Dhabi, UAE

UAE-Based Speakers

Mrs. Bodour Al Nawajha
Diploma in Special Education and a Mother of Child with Christianson Syndrome, Dubai, UAE

Ms. Dana Hammad
Biotechnologist, Sciences College, Sharjah University, Sharjah, UAE

Mrs. Dianne Alameddine
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Prof. Eman Gaad
Dean of Faculty of Education and Professor of Special and Inclusive Education, British University in Dubai, Dubai, UAE

Ms. Fatima Al Sakkaf
Health Program Specialist, Special Olympics UAE, Abu Dhabi, UAE

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UAE-Based Speakers

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Mrs. Hala Abass
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Dr. Hana Al Geilani
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UAE-Based Speakers

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Dr. Hassan Jaafar
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UAE-Based Speakers

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Mrs. Karen Kehdy
Neurodiversity Advocate, Writer, and Mother of Two Neurodivergent Children, Dubai, UAE

UAE-Based Speakers

Prof. Khaled Musallam
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Adj Professor, Khalifa University, Abu Dhabi, UAE
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Dr. Khawla Al Shehhi
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UAE-Based Speakers

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

Mr. Majid Jafar
Co-Founder, Loulou Foundation, UAE

Mrs. Mandy Sunner
Co-Founder, Digital Lead, and Research Advocate, PTLS Hope Research Foundation and Mother for Child with Potocki-Lupski Syndrome, Dubai, UAE

Ms. Maria Antonela Axinte
Genetic Counselor and Founder, DNA Longevity, Dubai, UAE

Dr. Mehtab Iqbal
Consultant Paediatric Neurologist & Division Chief Tawam Hospital, Al Ain, Abu Dhabi, UAE

Dr. Mohamad Al Hakim
Founder and Chairman, American Spine Center, Dubai, UAE

Prof. Mohamad Miqdady
Division Chief & Consultant, Pediatric Gastroenterology, Sheikh Khalifa Medical City
Clinical Professor, Khalifa University, Abu Dhabi, UAE

Mr. Mohamad Rammal
Co-founder and CEO, CureLeads, Dubai, UAE

UAE-Based Speakers

Dr. Mohamed Abuhaleeqa
Consultant Hematology and Bone Marrow Transplant and Chair of Academic Affairs Department, Abu Dhabi Stem Cells Center (ADSCC), Abu Dhabi, UAE

Prof. Mohamed Abuzakouk
Department Chair and Consultant, Allergy and Clinical Immunology, Cleveland Clinic Abu Dhabi, Abu Dhabi, UAE

Dr. Mohamed Ebrahim
Consultant Allergy and Immunology, Danat Al Emarat Hospital, Abu Dhabi, UAE

Prof. Mohamed Farghaly
Consultant Family Medicine and Diabetes Management, Dubai Health Authority
Scientific Chairman, Emirates Family Medicine Society
Professor of Medicine, Dubai Medical College, Dubai, UAE

Dr. Mohammad Yousuf
Pharmacist, Clinical Pharmacy Department, Sheikh Shakhbout Medical City, Abu Dhabi, UAE

Dr. Muhammad Tahir
Consultant Psychiatrist and Neurologist and Director, American Wellness Center, Dubai, UAE

Dr. Muna Al Saffar
Director of Genetic Counseling Program, Assistant Professor, and DOH Licensed and Canadian Board Certified Genetic Counselor, Department of Genetic and Genomics, College of Medicine and Health Sciences, United Arab Emirates University, Al Ain, UAE

Dr. Mustafa Al Baroudi
Consultant Pediatric Hematology and Oncology, NMC Royal Hospital, Abu Dhabi, UAE

UAE-Based Speakers

Dr. Nameer Al-Saadawi
Deputy Chief Medical Officer and Clinical Director of Abu Dhabi Bone Marrow Transplant Program, Abu Dhabi Stem Cell Center, Abu Dhabi, UAE

Mrs. Nashmeya Al-Fili
International Coach Special Education, Artist, Specialized Writer for People of Determination, Member of the Emirates Society for Rare Diseases, Member of Read and Enjoy Center Department of Support for People of Determination, Administrator in the Arab Mothers of Heroes Group, and Mother of Child with Cornelia de Lange Syndrome, Dubai, UAE

Ms. Nipa Bhuptani
Founder and Chief Values Officer, Applied & Behavioral Training Institutes, Abu Dhabi, UAE

Ms. Noura Alblooki
Senior Editor, Social Media, Abu Dhabi Media Network, Abu Dhabi, UAE

Dr. Omar Alsokhni
Pharmacy Manager, Inpatient Services, Cleveland Clinic Abu Dhabi, Abu Dhabi, UAE

Dr. Omar Ismayl
Division Head & Consultant, Pediatric Neurology Sheikh Khalifa Medical City, Abu Dhabi, UAE

Prof. Pierre Krystkowiak
Consultant Neurology, Specialized Rehabilitation Center, Capital Health, Abu Dhabi, UAE
Professor of Neurology, University of Picardie, Amiens, France
Professor of Neurology, Khalifa University, Abu Dhabi, UAE

Prof. Rabih Halwani
Director, Research Institute for Medical and Health Sciences, University of Sharjah
Professor, College of Medicine, University of Sharjah, Sharjah, UAE

UAE-Based Speakers

Ms. Ramola Talwar Badam
Communities Editor, The National, Abu Dhabi, UAE

Mrs. Rana Abu Khadra
Business Excellence Consultant, Co-founder of CureSCG, and Mother of Child with Limb Girdle Muscular Dystrophy, Abu Dhabi, UAE

Dr. Rania Al Dweik
Associate Professor in Public Health and Epidemiology and Associate Dean of Academic Affairs, College of Health Sciences, Abu Dhabi University, Abu Dhabi, UAE

Dr. Rasha Abdelrahman
Head of Psychology Department & Assistant Professor, College of Humanities and Sciences, Ajman University, Ajman, UAE

Prof. Rasheed Alhammadi
Advisor Research and Innovation Center, Center of Research and Innovation, Abu Dhabi Department of Health, Abu Dhabi, UAE

Dr. Rawia Mohamed
Head of Department and Consultant, Anatomical Pathology, Burjeel Medical City, Abu Dhabi, UAE

Mrs. Renate Baur-Richter
Executive Director, Access for All - Institute for Accessibility and Inclusion, Abu Dhabi, UAE

Mr. Rifaat Rawashdeh
DOH Licensed, ABGC Certified Genetic Counselor, Oncology Institute, Cleveland Clinic Abu Dhabi, UAE

UAE-Based Speakers

Mrs. Rola Jamal Al Naanaa
Student at the National Academy for Childhood Development and Mother of Child with Muscle-Eye-Brain Disorder, Abu Dhabi, UAE

Dr. Safeya Algharebi
Specialist Pediatric Dentistry, Al Mushrif Children's Specialty Center, SEHA, Abu Dhabi, UAE

Prof. Shahrukh Hashmi
Director of Research, Department of Health, Abu Dhabi, UAE
Professor of Medicine, Mayo Clinic Alix School of Medicine, Rochester, Minnesota, USA

Dr. Shaikha Almazrouei
Researcher of Genomics, Technology Innovation Institute, Abu Dhabi, UAE

Dr. Shiamaa Almashhadani
Senior Specialist Public Health Dentistry, Head of Promotion and Prevention, and Clinical lead for Dental Home Services, Dubai Health
Dental Internship Supervisory Program, Hamdan Bin Mohammed College of Dental Medicine, Mohammed Bin Rashid University (HBMCDM-MBRU), Dubai, UAE

Ms. Shija Sapru
Neurodiversity and Strength-Based Approach Advocate, Certified in Twice Exceptional (2e) Education from Bridges Graduate School, and Supporter of Alternative Schooling Approaches, Dubai, UAE

Dr. Shivam Mittal
Section Head and Consultant Neurologist, Parkinson Disease & Movement Disorders Program, Cleveland Clinic Abu Dhabi, Abu Dhabi, UAE

Mrs. Shruti Shenbagam
Certified Genetic Counselor, Al Jalila Children's Specialty Hospital, Dubai, UAE

UAE-Based Speakers

Mrs. Sonika Sachanandani-Phulwani
Licensed Genetic Counselor, M42 (Biogenix), Abu Dhabi, UAE

Ms. Souad Fares
Head of Special Education, Awladouna Center for People of Determination, Sharjah, UAE

Ms. Tanuka Gupta
Neuroaffirming Senior Clinical Psychologist, Al Noor Training Centre for People of Determination, Dubai, UAE

Dr. Tarek El-Azzabi
Consultant Pediatrics and Neurodisability, Pediatric Department, Sheikh Khalifa Medical City, Abu Dhabi, UAE
Clinical Assistant Professor of Pediatrics, College of Medicine and Health Sciences, UAE University, Al Ain, UAE

Mr. Wael Al Awabdah
Behavior Analyst, Special Olympics UAE, Abu Dhabi, UAE

Dr. Yahya Kiwan
Senior Consultant Interventional Cardiologist and Stem Cells and Regenerative Medicine Specialist, Dr Sulaiman Al Habib Hospital, Dubai, UAE
Assistant Professor, University of Sharjah, Sharjah, UAE
Program Director, American Board of Regenerative Medicine Fellowship

Dr. Yaser Sabsabi
Chief Revenue Cycle Officer, Saudi German Hospital Group, Dubai, UAE

Ms. Yasmin Mitwally
Research and Advocacy Manager, National Multiple Sclerosis Society, Abu Dhabi, UAE

UAE-Based Speakers

Mr. Youssef Hussiny
CEO, Tapy, Dubai, UAE

Dr. Zaid Al Aubaidi
Consultant Orthopedics & Pediatric Spine Surgery
Unit Head, Pediatric Orthopedics & Spine, Al Zahra Hospital, Dubai, UAE

Dr. Zeinab Alloub
Consultant Pediatric Neurodevelopment, Al Jalila Children's Speciality Hospital
Assistant Professor, Mohammed Bin Rashid University of Medicine and Health Sciences, Dubai, UAE

MENA Congress for RARE DISEASES 2025

17-20 April 2025, Beach Rotana Hotel, Abu Dhabi, UAE

IN PARTNERSHIP WITH BMC BURJEEL MEDICAL CITY

By Burjeel Holdings

Congratulations to the Abstract Winners

1

Dr. Lama AlAbdi

Scientist and Section Head of Developmental Genetics, Translational Genomics Department, Centre For Genomic Medicine, King Faisal Specialist Hospital and Research Centre, Riyadh, **Saudi Arabia**

2

Dr. Suki Malhi

Senior Vice President, Clinical Development Operations, Wave Life Sciences, Lexington, Massachusetts, **USA**

3

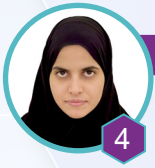
Ms. Ayat Kadhi

Lecturer, University of Doha for Science and Technology and PhD Candidate, Hamad Bin Khalifa University and Sidra Medicine, Doha, **Qatar**

4

Dr. Elena Zhekaite

Associate Professor and Senior Researcher, Research Centre for Medical Genetics, Moscow, **Russia**



4

Ms. Hind Almarri

Master of Genetic Counseling Student, College of Medicine and Health Sciences, United Arab Emirates University, Al Ain, **UAE**

4

Dr. M-Hossein Moeinzadeh

Guest scientist at Max Planck for Molecular Genetics and CTO and Co-Founder of Lucid Genomics, Berlin, **Germany**

5

Dr. Valerie Jacquemin

Geneticist Post-Doctoral Fellow, Human Genetics Department, CHU Liege, Liege, **Belgium**

Day 1: Thursday, 17 April 2025

Scientific Main Track: Al Thuraya A&B

Opening Session

Chairperson: Prof. Ayman El-Hattab

09:00 - 09:10	Opening remarks: MENA Congress for Rare Diseases	Prof. Ayman El-Hattab
09:10 - 09:30	Bridging global commitments and regional realities: the MENA region's role in shaping the impact of the world health assembly resolution on rare diseases	Ms. Alexandra Heumber Perry
09:30 - 10:00	Panel Discussion	Dr. Jennifer Jackson Ms. Alexandra Heumber Perry Dr. Soraya Bekkali Dr. Zahra Alsahlawi
10:00 - 10:30	Opening ceremony and award distribution	

10:30 - 11:00 Coffee Break

Satellite Symposium: Al Thuraya B

1st MENA Summit for Gene and Cell Therapy

Chairperson: Dr. Nameer Al-Saadawi

11:00 - 11:20	Revolutionizing healthcare: the rise of gene therapy in the UAE - ADSCC experience	Dr. Mohamed Abuhaleeqa
11:20 - 11:40	The promise of gene therapies for neuromuscular disorders: experience from Qatar	Prof. Tawfeg Ben-Omran
11:40 - 12:00	Stem cell therapy for cardiac diseases, the past, the present, the future	Dr. Yahya Kiwan
12:00 - 12:20	Is the stem cell the hope for neurodegenerative disorder	Dr. Mohamad Al Hakim
12:20 - 12:40	Cord blood unit is not just a bag of blood	Dr. Hatim Sidahmed
12:40 - 01:00	Future of cell and gene therapy for rare diseases	Dr. Shaikha Almazrouei

Satellite Symposium: Al Thuraya A

1st MENA Summit for the Limb Girdle Muscular Dystrophies

Chairperson: Prof. Nicholas Johnson

11:00 - 11:20	Overview and management of limb girdle muscular dystrophies	Prof. Nicholas Johnson
11:20 - 11:40	The Egyptian experience with limb girdle muscular dystrophies	Dr. Rasha El-Sherif
11:40 - 12:00	Genetic testing and other diagnostics in limb girdle muscular dystrophies	Dr. Samuel Carrell
12:00 - 12:20	The role of physical therapy and exercise in management of limb girdle muscular dystrophies	Dr. Michael Kiefer
12:20 - 12:40	The development of gene therapies in limb girdle muscular dystrophies	Dr. Ellie Carrell
12:40 - 01:00	Success of genetic and other precision therapies in related conditions	Dr. Arturo Saavedra

Satellite Symposium: Al Thuraya C

2nd MENA Summit for Genetic Counselors - Part 1

Chairperson: Dr. Muna Al Saffar

11:00 - 11:20	The role of genetic counselors in genomic era	Dr. Muna Al Saffar
11:20 - 11:40	The changing face of genetic counseling in the era of precision medicine: experience from Qatar	Dr. Reem Al-Sulaiman
11:40 - 12:00	Genetic counselling achievements and milestones: insights from the Oman	Ms. Khalsa Al-Kharusi
12:00 - 12:20	The power of pedigrees: genetic counseling and family studies in rare diseases	Dr. Maryem Ismail
12:20 - 12:40	Genetic counseling in reproductive decision-making	Ms. Laura Paquette
12:40 - 01:00	Savings by genetic counselors in a tertiary pediatric hospital	Mrs. Shruti Shenbagam

01:00 - 02:00 Lunch Break

Satellite Symposium: Al Thuraya B

1st MENA Summit for Hemoglobinopathies

Chairperson: Prof. Khaled Musallam

02:00 - 02:20	Beta-thalassemia in the era of disease-modifying therapies	Prof. Ali Taher
02:20 - 02:40	Alpha-thalassemia revisited	Dr. Abdullah Al Zayed
02:40 - 03:00	Novel targets for pharmacologic management of sickle cell disease	Prof. Salam Alkindi
03:00 - 03:20	Iron overload in hemoglobinopathies: conquered or forgotten?	Prof. Mohamed Yassin
03:20 - 03:40	Hemoglobinopathies burden in the UAE	Dr. Hany Dewedar
03:40 - 04:10	BMS Sponsored Medical Symposium - Innovations in beta thalassemia: redefining patient outcomes	Prof. Ali Taher

Satellite Symposium: Al Thuraya A

1st MENA Summit for Autism and Neurodivergence

Chairperson: Ms. Tanuka Gupta

02:00 - 02:20	Neurodiversity 101: The spectrum of human minds and body	Mrs. Karen Kehdy
02:20 - 02:40	Understanding and embracing neurodivergence: key to fostering neuroinclusive spaces	Dr. Haneesha Pinnamaraju
02:40 - 03:00	Neuroaffirming approach: shifting from a deficit-lens to a strength-based approach	Ms. Shija Sapru
03:00 - 03:20	What causes autism? - Let's try again	Dr. Arif A. Khan
03:20 - 03:40	My journey as an artist on the autism spectrum	Mr. Abdulla Lutfi
03:40 - 04:00	ADHD wonders	Dr. Hana Al Geilani

Satellite Symposium: Al Thuraya C

2nd MENA Summit for Genetic Counselors - Part 2

Chairperson: Mr. Rifaat Rawashdeh

02:00 - 02:20	Cancer genetic counseling service outcomes: a single center experience in Abu Dhabi	Mr. Rifaat Rawashdeh
02:20 - 02:40	Ethical dilemmas and psychosocial considerations in genetic counseling: navigating IVF in the Arab world	Mrs. Dianne Alameddine Ms. Lea Abed
02:40 - 03:00	The utility of rapid whole genome sequencing in an ICU setting	Mr. Alan Taylor
03:00 - 03:20	The role of genetic counseling in addressing age-related diseases	Ms. Maria Antonela Axinte
03:20 - 03:40	Bridging the gap: the lab genetic counselor's experience and impact	Mrs. Sonika Sachanandani-Phulwani
03:40 - 04:00	A guide to effective engagement in the Arab world: strategies for genetic counselors, experts, and scientists	Mrs. Hibat Omer

04:00 - 04:30 Coffee Break

Satellite Symposium: Al Thuraya A

1st MENA Summit for Inclusion and Diversity

Chairperson: Mrs. Renate Baur-Richter

04:30 - 04:50	Innovation in action: how technology is reshaping inclusion for people of determination	Mrs. Renate Baur-Richter
04:50 - 05:10	The role of stakeholders in shaping inclusive frameworks	Mr. Johannes Loh
05:10 - 05:30	Redefining inclusion: sustainable business models by people of determination within and beyond corporations and government	Dr. Alberto Peralta
05:30 - 05:50	From awareness to action: strategies for workplace inclusion for people with multiple sclerosis and other people of determination	Ms. Yasmin Mitwally
05:50 - 06:10	Disability representation in media through a Middle Eastern lens	Ms. Noura Alblooki

برنامج تدريبي: قاعة الثريا ج

المدرسة الحسية وبرتوكول بوب لتأهيل الحواس (اليوم الأول)

رئيس الجلسة: أ.د بهاء الدين جلال

05:30 - 09:30	النظرية الحسية في تعلم أصحاب الهمم والتغير في نظام التعليم	أ.د بهاء الدين جلال

Day 2: Friday, 18 April 2025

Scientific Concurrent Session: Al Thuraya B

Rare Ophthalmologic Disorders

Chairperson: Dr. Rola Ba-Abbad

08:30 - 08:50	The clinical and mutational spectrum of Bardet-Biedl syndrome in Saudi Arabia	Dr. Rola Ba-Abbad
08:50 - 09:10	When pediatric cataract is a sign of undiagnosed systemic disease	Prof. Arif O. Khan
09:10 - 09:30	Navigating retinal disorders in a pediatric ophthalmology clinic	Dr. Imran Jawaid

Community Support Session: Al Thuraya A

Psychosocial Challenges in Rare Diseases

Chairperson: Prof. Rasheed Alhammadi

08:30 - 08:50	Holistic and innovative approaches to psychiatric care in rare diseases	Dr. Hamid Alhaj
08:50 - 09:10	The psychosocial impact of rare diseases among children and adolescents: the role of teachers and parents for psychosocial and educational support	Prof. Ghanem Al Bustami
09:10 - 09:30	Psychiatric support for children with rare diseases: addressing developmental and emotional needs	Dr. Muhammad Tahir

Training Program: Al Thuraya C

Intimaa

Chairperson: Ms. Nipa Bhuptani

08:30 - 01:00	Intimaa: A transformative initiative to empower organizations, designed to break bias, shift attitudes, and change mindsets about inclusivity. Brought to you by Maan Certified Social Enterprise: Applied & Behavioral.	Ms. Nipa Bhuptani Ms. Amina Maliki

Scientific Concurrent Session: Al Thuraya B

Rare Malignancies

Chairperson: Dr. Hassan Jaafar

09:30 - 09:50	Treatment approaches and implementation for mismatch repair cancer syndrome	Dr. Hassan Jaafar
09:50 - 10:10	Neuroendocrine tumors in the UAE, rare but not too rare	Prof. Humaid Al-Shamsi
10:10 - 10:30	Rare malignancies in children	Dr. Mustafa Al Baroudi

Community Support Session: Al Thuraya A

Patient Advocacy for Rare Diseases

Chairperson: Mrs. Hanaa El-Sadat

09:30 - 09:50	Yasmin Elsamra Foundation: transforming lives through compassion	Mrs. Hanaa El-Sadat
09:50 - 10:10	Patient-led drug development for a rare disease	Mr. Majid Jafar
10:10 - 10:30	Galactosialidosis, a metabolic disease, and the road to therapy through international collaboration	Mr. Cagdas Canbolat

10:30 - 11:00 Coffee Break

Scientific Main Track: Al Thuraya A&B

Keynote Presentations on Rare Diseases

Chairperson: Dr. Joanne Sadier

11:00 - 11:20	Clinical and genomic approaches for unsolved and undiagnosed rare diseases	Prof. Uğur Özbek
11:20 - 11:40	Diagnostic clues of rare genetic disorders promote target gene sequencing	Prof. Maha Zaki
11:40 - 12:00	The faces of genetics in the mirror of consanguinity	Prof. Zuhair Al-Hassnan
12:00 - 12:20	Genomics: unlocking the mechanism of rare diseases	Dr. Cristina Skrypnyk
12:20 - 12:40	The intersection of clinical practice and research: towards patient-centered care	Prof. Tawfeg Ben-Omran
12:40 - 01:00	The use of metagenomics in assessing the epigenetic impacts on rare diseases	Prof. Mahir Al-Hilali

01:00 - 02:00 Lunch Break

Scientific Main Track: Al Thuraya A&B

Newborn Screening and Rare Diseases

Chairperson: Prof. Osama Aldirbashi

02:00 - 02:20	Newborn screening: pitfalls and challenges	Dr. Pascale Karam
02:20 - 02:40	A decade of newborn screening in Kuwait: lessons learned and future directions	Dr. Hind Alsharhan
02:40 - 03:00	Newborn screening in Bahrain: current status and efforts for best neonatal health	Dr. Zahra Alsahlawi

Scientific Main Track: Al Thuraya A&B

Best Practices for Management of Rare Diseases

Chairperson: Prof. Asma Deeb

03:00 - 03:20	Best practice in management of rare forms of diabetes	Prof. Asma Deeb
03:20 - 03:40	Identifying unique rare disease patients in Saudi Arabia, the ENPP1 story and a phase III trial	Dr. Afaf Alsagheir
03:40 - 04:00	Best practices in the management of pediatric pulmonary hypertension	Dr. Anas Abu Hazeem
04:00 - 04:20	Management of orthopedic conditions in patients with rare diseases	Dr. Zaid Al Aubaidi

04:00 - 04:30 Coffee Break

Scientific Concurrent Session: Al Thuraya B

Rare Immune Diseases

Chairperson: Prof. Mohamed Abuzakouk

04:30 - 04:50	Combined immunodeficiency disorders	Dr. Hiba Shendi
04:50 - 05:10	Hereditary angioedema: diagnosis and novel treatment	Dr. Hamad Alhameli
05:10 - 05:30	Immune check point deficiencies and autoimmune lymphoprelifrative syndromes (ALPS)	Dr. Mohamed Ebrahim

Community Support Session: Al Thuraya A

Media Awareness and Rare Diseases

04:30 - 05:30	Panel discussion	Dr. Abeer Al Naqbi Dr. Bassam Darwish Ms. Ramola Talwar Badam

Scientific Concurrent Session: Al Thuraya C

The knowns and the unknowns in rare diseases

Chairperson: Dr. Anwar Baban

04:30 - 04:40	Introduction	Dr. Anwar Baban
04:40 - 04:50	Anorexia Nervosa and Body Image	Prof. Haleama Al Sabbah
04:50 - 05:00	Rare X-linked disease: Lesch-Nyhan syndrome	Ms. Dana Hammad
05:00 - 05:10	Rare case of NONO-associated X-linked intellectual disability syndrome	Dr. Kuldeep Dhariwal
05:10 - 05:20	Case of limbic encephalitis	Dr. Himanshu Soni
05:20 - 05:30	Case study: Tyrosinemia type 1 or Maleylacetoacetate Isomerase deficiency? Insights from Quebec's founder effect	Dr. Farah ElTurk
05:30 - 05:40	Rare to uncommon - mutations and phenotype in osteogenesis imperfecta: a short case series	Dr. Sreelata Nair

برنامج تدريبي: قاعة الثريا ج

المدرسة الحسية وبرتوكول بوب لتأهيل الحواس (اليوم الثاني)

رئيس الجلسة: أ.د بهاء الدين جلال

05:30 - 09:30	برتوكول بوب لتأهيل الحواس لأصحاب الهمم	أ.د بهاء الدين جلال

Day 3: Saturday, 19 April 2025

Scientific Concurrent Session: Al Thuraya B

Dental Care for Rare Diseases

Chairperson: Dr. Shiamaa Almashhadani

08:30 - 08:50	Multidisciplinary approach to dental treatment of individuals with rare diseases	Dr. Shiamaa Almashhadani
08:50 - 09:10	Dental manifestations of rare diseases and their management	Dr. Ilhaam Abbas
09:10 - 09:30	Behavior management techniques in dentistry for people of determination	Dr. Safeya Algharebi

Scientific Concurrent Session: Al Thuraya B

Rehabilitation for Rare Diseases

Chairperson: Dr. Binu George

09:30 - 09:50	Basic principles of rehabilitation in rare diseases	Dr. Binu George
09:50 - 10:10	Rehabilitation for neuromuscular disorders	Prof. Haitham Elbashir
10:10 - 10:30	Sleep disturbances in children with neurodevelopmental disorders	Dr. Tarek El-Azzabi

Scientific Concurrent Session: Al Thuraya A

Pharmacoeconomics and Access to Orphan Drugs in Rare Diseases

Chairperson: Dr. Mohammad Yousuf

08:30 - 08:50	Pharmacoeconomics on rare diseases: a focus on UAE healthcare system	Dr. Mohammad Yousuf
08:50 - 09:10	Balancing costs and benefits: pharmacoeconomic evaluation of orphan drugs versus supportive care for rare diseases	Dr. Omar Alsokhni
09:10 - 09:30	Differential pricing and reimbursement approach for innovative medication	Dr. Adel Al Assy
09:30 - 09:50	Access to high cost medications	Prof. Mohamed Farghaly
09:50 - 10:10	Access to orphan drugs: what is the next step?	Dr. Gihan Elsisi
10:10 - 10:30	Managing the access paradox: what comes first	Mr. Mohamad Rammal

10:30 - 11:00 Coffee Break

Scientific Main Track: Al Thuraya A&B

Updates on Diagnostics for Rare Diseases

Chairperson: Prof. Bassam Ali

11:00 - 11:20	The power of rare disease diagnostics	Dr. David Kasper
11:20 - 11:40	Laboratory diagnostic approach in inborn errors of metabolism	Prof. Osama Aldirbashi
11:40 - 12:00	The future of rare disease diagnostics: insights from histopathology	Dr. Rawia Mohamed

Scientific Main Track: Al Thuraya A&B

Artificial Intelligence and Rare Diseases

Chairperson: Prof. Bassam Ali

12:00 - 12:20	Unlocking genetic mysteries: revolutionizing rare disease diagnosis with machine learning	Dr. Imane Boudellioua

01:00 - 02:00 Lunch Break

Scientific Main Track: Al Thuraya A&B

Novel Therapies for Rare Diseases

Chairperson: Prof. Jordi Surralles

02:00 - 02:20	Genomic medicine in Fanconi anemia: from genes to drug repurposing and advanced therapies	Prof. Jordi Surralles
02:20 - 02:40	Treatable metabolic and genetic disorders mimicking cerebral palsy	Prof. Brahim Tabarki Melaiki

04:00 - 04:30 Coffee Break

Scientific Concurrent Session: Al Thuraya B

Nutritional Support for Rare Diseases

Chairperson: Prof. Mohamad Miqdady

04:30 - 04:50	Metabolic disorders: when and what to feed	Prof. Mohamad Miqdady
04:50 - 05:10	Nutritional challenges in managing rare diseases	Prof. Haleama Al Sabbah

Community Support Session: Al Thuraya A

Insurance Coverage for Rare Diseases

04:30 - 05:30	Panel Discussion	Prof. Eman Gaad Dr. Rania Al Dweik Dr. Yaser Sabsabi

برنامج تدريبي: قاعة الثريا ج

المدرسة الحسية وبرتوكول بوب لتأهيل الحواس (اليوم الثالث)

رئيس الجلسة: أ.د بهاء الدين جلال

05:30 - 09:30	برتوكول بوب لعلاج الحواس لأصحاب الهمم	أ.د بهاء الدين جلال

Day 4: Sunday, 20 April 2025

Disease-Specific Symposium: Al Thuraya B

3rd MENA Summit for Huntington Disease

Chairperson: Mr. Svein Olaf Olsen

08:30 - 08:50	Huntington in the MENA region: the way forward	Mr. Svein Olaf Olsen
08:50 - 09:10	Approach to chorea: steps for diagnosis	Dr. Shivam Mittal
09:10 - 09:30	Update on Huntington disease upcoming treatments	Prof. Pierre Krystkowiak
09:30 - 09:50	Human dental pulp stem cells as a therapeutic avenue for Huntington disease: the promise of NestaCell®	Prof. Rodrigo Pinheiro Araldi
09:50 - 10:30	Discussion	

Disease-Specific Symposium: Al Thuraya A

3rd MENA Summit for Angelman Syndrome

Chairperson: Dr. Zeinab Alloub

08:30 - 08:50	Medical surveillance in Angelman syndrome	Dr. Zeinab Alloub
08:50 - 09:10	Evolution of epilepsy and EEG findings in Angelman syndrome	Dr. Majid Aziz
09:10 - 09:30	The Angelman syndrome therapeutic pipeline	Mrs. Amelia Beatty
09:30 - 10:00	Panel discussion	Mrs. Ellen Koekoeckx
10:10 - 10:30	جلسة حوارية	الدكتورة فداء ذياب د. رشا عبدالرحمن الأستاذة سعاد فارس

Training Program: Al Thuraya C

Unified Healthcare Training

Chairperson: Mrs. Areen Abuhejleh

08:30 - 05:00	Unified healthcare training: empowering medical and patient interfacing professionals to provide compassionate healthcare to people of determination	Mrs. Areen Abuhejleh Ms. Fatima Al Sakkaf Ms. Lama Ayoub Mr. Wael Al Awabdah

10:30 - 11:00 Coffee Break

Scientific Main Track: Al Thuraya B

Research and Innovation in Rare Diseases

Chairperson: Prof. Khaled Musallam

11:00 - 11:20	The role of international collaborations in rare disease research	Prof. Ali Taher
11:20 - 11:40	Research on rare genetic disease in UAE: challenges and opportunities	Prof. Rabih Halwani
11:40 - 12:00	Nuts and bolts of clinical trials in rare diseases	Prof. Shahrukh Hashmi
12:00 - 12:10	Abstract, 1st Place: Arab founder variants: Contributions to clinical genomics and precision medicine	Dr. Lama AlAbdi
12:10 - 12:20	Abstract, 2nd Place: Interim data following 24 weeks of treatment with WVE-N531 in the phase 2 open-label forward-53 Study	Dr. Suki Malhi Dr. Kuldeep Singh
12:20 - 12:30	Abstract, 3rd Place: Genomic landscape of inherited bone marrow failure syndromes: Insights from the first multi-center registry and a large Middle Eastern biobank	Ms. Ayat Kadhi
12:30 - 12:40	Abstract, 4th Place: The effectiveness of the CFTR-modulator elexacaftor/tezacaftor/ivacaftor in children according to the results of 2-year therapy	Dr. Elena Zhekaite
12:40 - 12:50	Abstract, 4th Place: Voices in practice: Exploring genetic counseling ethical, cultural, social, and religious dynamics in the UAE	Ms. Hind Almarri
12:50 - 01:00	Abstract, 4th Place: Accurate detection of pathogenic structural variants guided by multi-platform comparison	Dr. M-Hossein Moeinzadeh
01:00 - 01:10	Abstract, 5th Place: BabyDetect: NBS for rare disease using tNGS – a Belgian study	Dr. Valerie Jacquemin

قاعة الثريا أ

الملتقى الأول لدعم وإسعاد أسر الأمراض النادرة

تحت رعاية وحضور سمو الشيخة عايشة بنت عبيد بن بطي المكتوم

11:00 - 11:05	كلمة الترحيب	الاستاذ الدكتور أيمن الحطاب
11:05 - 11:10	كلمة الأفتتاح	سمو الشيخة عايشة بنت عبيد بن بطي المكتوم
11:15 - 11:20	أمهات ملهمات في مجال الأمراض النادرة	الدكتورة فداء ذياب
11:20 - 11:30	تكريم الأمهات الملهمات في أسر الأمراض النادرة	
11:30 - 11:45	لماذا نستخدم ساعة تابي أمان	الاستاذ يوسف الحسيني
11:45 - 12:00	تجربتي مع ساعة تابي أمان	الدكتورة فداء ذياب
12:00 - 12:15	توزيع ساعات تابي امان على أصحاب الأمراض النادرة	
12:15 - 01:00	ورشة عمل عن كيفية استعمال ساعة تابي أمان	الاستاذ يوسف الحسيني

01:00 - 02:00 Lunch Break

Disease-Specific Symposium: Al Thuraya B

3rd MENA Summit for Duchenne Muscular Dystrophy

Chairperson: Dr. Mehtab Iqbal

02:00 - 02:20	Duchenne muscular dystrophy: an overview of manifestations and importance of early diagnosis	Dr. Mehtab Iqbal
02:20 - 02:40	Duchenne muscular dystrophy and standards of care	Dr. Karolina Podolska
02:40 - 03:00	Current and future therapies for Duchenne muscular dystrophy	Dr. Omar Ismayl
03:00 - 03:20	The Duchenne community: education and networking	Ms. Nicoletta Madia
03:20 - 04:00	Discussion	

Patients & Families Meeting: Al Thuraya A

3rd MENA Rare Disease Symposium for Patients and Families

Chairperson: Dr. Khawla Al Shehhi

02:00 - 02:20	Genetic diseases: inheritance and diagnosis	Dr. Heba Elabd
02:20 - 02:40	Acceptance and coping strategies for psychological distress: life skills for parents of people of determination	Dr. Rasha Abdelrahman
02:40 - 03:00	The effect of nutritional interventions on rare disease	Ms. Hadeel Iraq

اجتماع المرضى والعائلات: (قاعة الثريا أ)

الملتقى الثالث للأمراض النادرة في الشرق الأوسط وشمال افريقيا للمرضى وعائلاتهم

رئيس الجلسة: د. خولة الشحي

03:00 - 03:20	أمراض الجينات: طرق الوراثة والتشخيص	د. هبة العبد
03:20 - 03:40	التقبل والتعامل مع الضغوط النفسية: بعض المهارات الحياتية لاهالي ذوي الإعاقة	د. رشا عبدالرحمن
03:40 - 04:00	تأثير التدخلات الغذائية على الأمراض النادرة	السيدة هديل عراق

04:00 - 04:30 Coffee Break

Patients & Families Meeting: Al Thuraya A

Connecting Voices: Experiences and Insights

Chairperson: Mrs. Rana Abu Khadra

04:30 - 04:40	Our journey from birth to today	Mrs. Hanan Hirst
04:40 - 04:50	What I didn't expect raising a child with Cri Du Chat	Mrs. Laura Laugier
04:50 - 05:00	Rett syndrome: a perspective	Mrs. Jinu Rachel John
05:00 - 05:10	PTLS Hope: our journey from diagnosis to discovery – building a foundation for a brighter future	Mrs. Mandy Sunner
05:10 - 05:20	Caregiver of patient with rare disease	Mrs. Annie Kapinda
05:20 - 05:30	مجموعه الأمراض النادرة: تحديات وطموح	السيدة أسماء سعيد راشد الإسماعيلية
05:30 - 05:40	وجوه من الميتوكندريا: فهم اضطرابات الميتوكوندريا	السيدة هالة عباس
05:40 - 05:50	جرعة أمل	السيدة بدور النواجحة
05:50 - 06:00	رحلة التشخيص و بدايات رحلة الأمومة لطفل من ذوي الهمم	السيدة دعاء أبورزق
06:00 - 06:10	أنصتوا فأنا كورنيليا دي لانج	السيدة نشمية الفيلي
06:10 - 06:20	مراحل الصدمة من الرفض إلى القبول وأثرها على فرص العلاج	السيدة رولى جمال النعنع

برنامج تدريبي: قاعة الثريا ج

المدرسة الحسية وبرتوكول بوب لتأهيل الحواس (اليوم الرابع)

رئيس الجلسة: أ.د بهاء الدين جلال

05:30 - 09:30	برتوكول بوب لتنمية الحواس	أ.د بهاء الدين جلال

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RARE DISEASES INTERNATIONAL

مؤسسة زايد العليا لأصحاب الهمم Zayed Higher Organization for People of Determination

ISPD International Society of Pediatric Dermatology

GULF ACADEMY FOR MEDICAL TRAINING LLC

Maladies rares Héréditaires du Métabolisme Filière nationale de santé

الجمعية الوطنية للتصلب المتعدد National Multiple Sclerosis Society

IMPSN International MPS Network Mucopolysaccharide and Related Diseases

CureSCG Cure Sarcoglycanopathy

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