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
- 28 CME hours
- 50+ sessions
- 160+ speakers (including 70+ international experts)
- 1500+ expected attendance

IN COLLABORATION WITH:

MENA Organization for RARE DISEASES

Educate • Connect • Support

ORGANIZED BY:

PEARL EVENT MANAGEMENT SERVICES

www.menararediseases.com

Welcome Letter

Prof. Ayman El-Hattab

Congress President, MENA Congress for Rare Diseases 2025
Director and Consultant Clinical Genetics, Genetics and Rare Disease Center,
Burjeel Medical City, Abu Dhabi
Professor, College of Medicine, University of Sharjah, Sharjah
Founder and President, MENA Organization for Rare Diseases, 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.

Welcome Letter

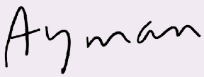
Our upcoming meeting, **MENA Congress for Rare Diseases 2025 in partnership with Burjeel Medical City**, Beach Rotana Abu Dhabi, 17-20 April 2025, will continue to be the largest event for rare diseases in the region. It will last for 4 full days with more than 160 speakers including more than 70 international 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.



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
- 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
Director and Consultant Clinical Genetics, Genetics and Rare Disease Center, Burjeel Medical City, Abu Dhabi
Professor, College of Medicine, University of Sharjah, Sharjah
Founder and President, MENA Organization for Rare Diseases, 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
Consultant Medical Genetics and Genomics, Al Jawhara Center for Molecular Medicine, Genetics & Inherited Disorders, Assistant Professor of Molecular Medicine, Arabian Gulf University & University Medical Clinics, Chair, Rare Disease Campaign & Care for Rare Support Group, Manama, Kingdom of Bahrain

Dr. Hind Alsharhan
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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

Dr. Pascale Karam
Associate Professor of Clinical Pediatrics and Inborn Errors of Metabolism, Department of Biochemistry and Molecular Genetics; and Head of Inborn Errors of Metabolism Program, Department of Pediatrics and Adolescent Medicine, American University of Beirut Medical Center, Beirut, Lebanon

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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

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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
Head of Health Programs, Special Olympics UAE, Abu Dhabi, UAE

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

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Founder and President, MENA Organization for Rare Diseases, 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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Professor, Universitat Autonoma of Barcelona, Barcelona, Spain

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Clinical Professor, Khalifa University, Abu Dhabi, UAE

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Session and Symposium Chairpersons

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Dr. Muna Al Saffar
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Dr. Nameer Al-Saadawi
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Prof. Nicholas Johnson
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Prof. Osama Aldirbashi
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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
Advisor Research and Innovation Center, Center of Research and Innovation, Abu Dhabi Department of Health, Abu Dhabi, UAE

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

Session and Symposium Chairpersons

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DOH Licensed, ABGC Certified Genetic Counselor, Oncology Institute, Cleveland Clinic Abu Dhabi, UAE

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Dr. Shiamaa Almashhadani
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Dental Internship Supervisory Program, Hamdan Bin Mohammed College of Dental Medicine, Mohammed Bin Rashid University (HBMCDM-MBRU), Dubai, 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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Qatif Health Network, Qatif, Saudi Arabia

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
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Mrs. Asmaa Al-Ismailia
Head of the Family Support Group for Rare Diseases in Sultanate of Oman, Muscat, Oman

International Speakers

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Dr. Bahaa Jalal
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Director, Help Center for the Middle East and North Africa, Kuwait, Kuwait

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Adjunct Professor Pediatric Neurology, AlFaisal University, Riyadh, Saudi Arabia

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

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International Speakers

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International Speakers

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President of the International Huntington Association, Søgne, Norway
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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
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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
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Mr. Alan Taylor
Certified Genetic Counselor, Al Jalila Children's Specialty Hospital, Dubai, UAE

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

UAE-Based Speakers

Dr. Arif A. Khan
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Associate Professor, Mohammed Bin Rashid University of Medicine and Health Sciences, Dubai, UAE

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Dr. Bassam Darwish
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
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Ms. Dana Hammad
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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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Chair, Department of Family and Community Medicine and Behavioral Sciences, College of Medicine, University of Sharjah
Associate Professor of Psychiatry, College of Medicine, University of Sharjah, Sharjah, UAE

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UAE-Based Speakers

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Dr. Hasan Tawamie
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Dr. Hatim Sidahmed
Head of Cord Blood Bank, M42, Abu Dhabi, UAE

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Assistant Professor, College of Medicine and Health Sciences, United Arab Emirates University, Al Ain, UAE

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Medical Geneticist, Skin Biology Researcher, and Scientific Committee Member, UAE Genetic Disease Association, Dubai, UAE

Dr. Himanshu Soni
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UAE-Based Speakers

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

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

Dr. Ilhaam Abbas
Dentist with Pediatric and Special Care Privileges, Healthpoint hospital, Mubadala Healthcare, Abu Dhabi, UAE

Dr. Imane Boudellioua
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Mrs. Jinu Rachel John
Masters in Biomedical Genetics, Certified in Behavioral Therapy and Special Education, Project Lead in AMEA, and Mother of Child with Rett Syndrome, Dubai, UAE

UAE-Based Speakers

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Senior Consultant, Department of Public Health, Dubai Health Authority, Dubai, UAE

Mr. Johannes Loh
Director, Government and Public Sector, MENA Consulting Services, Ernst & Young Middle East, Abu Dhabi, UAE

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

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

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The British University in Dubai,
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Associate Epidemiologist at University of Gothenburg, Gothenburg, Sweden
Mother of Child with Myasthenia Gravis

Dr. Kuldeep Dhariwal
Consultant Pediatrics, NMC Specialty Hospital, Al Nahda, Dubai, UAE

Ms. Lama Ayoub
International Behavioral Consultant, Special Olympics UAE, Abu Dhabi, UAE

UAE-Based Speakers

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Founder of Neurodiverse Families Events and Mother of a Child with Cri du Chat Syndrome, Dubai, UAE

Ms. Laura Paquette
DOH Licensed & ABGC Certified Genetic Counselor, Abu Dhabi Health Services Company (SEHA), Abu Dhabi, UAE
Adjunct Lecturer, Department of Genetics & Genomics, College of Medicine and Health Sciences, United Arab Emirates University, Al Ain, UAE

Ms. Lea Abed
EBMG Certified and DHA Licensed Genetic Counselor, Igenomix, Dubai, UAE

Prof. Mahir Al-Hilali
Consultant Hematology and Laboratory Medicine, Medical Director of Mediclinic Precise, and Director of Laboratory Services, Mediclinic Middle East
Adjunct Clinical Professor of Laboratory Medicine, Mohammed Bin Rashid University of Medicine and Health Sciences, Dubai, UAE

Dr. Majid Aziz
Consultant Pediatric Neurologist, Sheikh Khalifa Medical City, Abu Dhabi, 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

UAE-Based Speakers

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

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

UAE-Based Speakers

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

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. 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

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

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

UAE-Based Speakers

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

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

UAE-Based Speakers

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

Mrs. Sanaa Alkurdi
Lead Clinical Dietitian, Burjeel Medical City 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

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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

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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: Significance of world health assembly resolution on rare diseases in MENA region

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	Ms. Alexandra Heumber Perry Dr. Soraya Bekkali Dr. Zahra Alsahlawi Dr. Jennifer Jackson
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. Hisham 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 epigenetics transgenerational inheritance	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

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	Cardiac tumors	Dr. Anas Abu Hazeem
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	MENA organization for rare diseases: Patients in the center of care	Dr. Khedidja Hedna
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	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	Parental whole exome sequencing: a comprehensive diagnostic approach to uncover genetic causes	Dr. Hasan Tawamie
11:40 - 12:00	Laboratory diagnostic approach in inborn errors of metabolism	Prof. Osama Aldirbashi
12:00 - 12:20	The future of rare disease diagnostics: insights from histopathology	Dr. Rawia Mohamed
12:20 - 12:40	Unlocking genetic mysteries: revolutionizing rare disease diagnosis with machine learning	Dr. Imane Boudellioua
12:40 - 01:00	Accelerating rare diseases diagnosis by overcoming data silos	Dr. Laura Furlong

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
02:40 - 03:10	Advances in spinal muscular atrophy care	Prof. Haitham Elbashir
03:10 - 03:30	Friedreich ataxia: understanding the disease background and recent advances in management	Dr. Shivam Mittal

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
05:10 - 05:30	Utility of single amino acid supplementation in metabolic disorders	Mrs. Sanaa Alkurdi

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 Mrs. Ellen Koekoeckx
09:30 - 10:00	Panel discussion	
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 - 11:40	Panel discussion: opportunities and challenges for rare disease research in the MENA region	Prof. Khaled Musallam Prof. Ali Taher Prof. Shahrukh Hashmi Mr. Islam El-Tantawy Dr. Azza Attia
11:40 - 11:50	Abstract, 1st Place: Arab founder variants: Contributions to clinical genomics and precision medicine	Dr. Lama AlAbdi
11:50 - 12:00	Abstract, 2nd Place: Interim data following 48 weeks of treatment with WVE-N531 in the phase 2 open-label forward-53 Study	Dr. Suki Malhi Dr. Kuldeep Singh
12:00 - 12:10	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
12:10 - 12:20	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
12:20 - 12:30	Abstract, 4th Place: Voices in practice: Exploring genetic counseling ethical, cultural, social, and religious dynamics in the UAE	Ms. Hind Almarri
12:30 - 12:40	Abstract, 4th Place: Accurate detection of pathogenic structural variants guided by multi-platform comparison	Dr. M-Hossein Moeinzadeh
12:40 - 12:50	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	The Duchenne community: education and networking	Ms. Nicoletta Madia
03:00 - 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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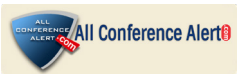

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Estd:2023, Kathmandu

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By Burjeel Holdings

BMC – Burjeel Medical City is a 400-bed multispecialty hospital and quaternary care center located in Abu Dhabi, UAE. It is the region's complex care hub with over 60 adult and pediatric specialties, aided by state-of-the-art medical technology and an international team of experts.

The 1.2 million-square-foot hospital is a flagship facility under the Burjeel Holdings umbrella. It is renowned for key specialties including oncology, hematology, bone marrow transplantation, neurosurgery, multi-organ transplantation, advanced orthopedic surgery, pediatric subspecialties, fetal medicine, nuclear medicine, and advanced gynecology.

The hospital is the first to receive ESMO accreditation as an Integrated Oncology and Palliative Care Center. It is also home to the Center for Research on Rare Blood Disorders (CR-RBD), one of the region's leading research hubs with a global portfolio of high impact publications, international guidelines, and various observational studies and clinical trials of novel therapeutics designed to improve the outcomes of patients with rare blood disorders.

Visit: https://burjeel.com/burjeelmedicalcity/

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ARCHIMEDlife®
International Medical Laboratory+

ARCHIMEDlife started in 2013 as an innovative and dynamic Medical Laboratory providing high quality, specialized diagnostic services for Rare Diseases and more in Vienna, Austria. Since then, more than 20,000 physicians in 75 countries have trusted in their services. ARCHIMEDlife works with prominent pharmaceutical companies in the orphan drug market. Thte company is committed to helping physicians and their patients avoid diagnostic odysseys by delivering novel, leading-edge, rapid testing services. In 2019 ARCHIMEDlife joined the amedes group, a German health care provider with over 4000 professionals running 80 laboratories and hospitals in Germany and Belgium. ARCHIMEDlife has recently expanded its portfolio to medical product distribution taking advantage of their broad network in DACH and Europe. With accreditation according to ISO 13485, ARCHIMEDlife operates as partner for diagnostic manufacturers developing and producing in-vitro diagnostics kits for market entry.

Bristol Myers Squibb™

Bristol Myers Squibb is a leading global biopharma company focused on discovering, developing and delivering innovative medicines for patients with serious diseases in areas including oncology, hematology, immunology, cardiovascular and neuroscience. Our employees work every day to transform patients' lives through science.

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AstraZeneca (LSE/STO/Nasdaq: AZN) is a global, science-led biopharmaceutical company that focuses on the discovery, development, and commercialisation of prescription medicines in Oncology, Rare Diseases, and BioPharmaceuticals, including Cardiovascular, Renal & Metabolism, and Respiratory & Immunology. Based in Cambridge, UK, AstraZeneca operates in over 100 countries and its innovative medicines are used by millions of patients worldwide.

Our Mission: Biogen is a leading biotechnology company that pioneers innovative science to deliver new medicines to transform patients' lives and to create value for shareholders and our communities.

We apply deep understanding of human biology and leverage different modalities to advance first-in-class treatments or therapies that deliver superior outcomes. Our approach is to take bold risks, balanced with return on investment to deliver long-term growth.

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First Genomix - Changing Lives Through Science

First Genomix (formerly known as Viafet Genomics Laboratory) is the leading provider of world-class genetic diagnostic services in the GCC and Middle East region. Since 2012, First Genomix has been extending its services to a wide network of local, regional, and international healthcare providers, offering unparalleled expertise in genetic testing using the most advanced molecular diagnostic technologies.

Committed to reducing the burden of genetic disorders in the community, First Genomix offers a comprehensive portfolio of highly specialized reproductive, prenatal, diagnostic, and screening solutions complemented by genetic counseling support from our highly qualified team of geneticists and professional counselors. Being the first laboratory in the GCC and Middle East to gain accreditation by the College of American Pathologists (CAP) for Next-Generation Sequencing technologies, First Genomix continually strives to expand its test offerings and streamline its workflows to provide physicians with better diagnostic insights that will help redefine and elevate the level of care delivered to patients.

Roche is a global pioneer in pharmaceuticals and diagnostics focused on advancing science to improve people's lives. The combined strengths of pharmaceuticals and diagnostics under one roof have made Roche the leader in personalised healthcare – a strategy that aims to fit the right treatment to each patient in the best way possible. Roche is the world's largest biotech company, with truly differentiated medicines in oncology, immunology, infectious diseases, ophthalmology and diseases of the central nervous system. Roche is also the world leader in in vitro diagnostics and tissue-based cancer diagnostics, and a frontrunner in diabetes management. Moreover, for the twelfth consecutive year, Roche has been recognised as one of the most sustainable companies in the Pharmaceuticals Industry by the Dow Jones Sustainability Indices (DJSI).

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WAVE™ LIFE SCIENCES

Wave Life Sciences is a biotechnology company focused on unlocking the broad potential of RNA medicines to transform human health.

Our RNA medicines platform, PRISM, combines multiple modalities, chemistry innovation and deep insights in human genetics to deliver scientific breakthroughs designed to treat both rare and prevalent disorders. Our diversified pipeline includes clinical programs in Duchenne muscular dystrophy, Alpha-1 antitrypsin deficiency, Huntington's disease, and obesity.

Driven by the calling to "Reimagine Possible", we are leading the charge toward a world in which human potential is no longer hindered by the burden of disease.

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agios

Agios is the pioneering leader in PK activation and is dedicated to developing and delivering transformative therapies for patients living with rare diseases. In the U.S., Agios markets a first-in-class pyruvate kinase (PK) activator for adults with PK deficiency, the first disease-modifying therapy for this rare, lifelong, debilitating hemolytic anemia. Building on the company's deep scientific expertise in classical hematology and leadership in the field of cellular metabolism and rare hematologic diseases, Agios is advancing a robust clinical pipeline of investigational medicines with programs in alpha- and beta-thalassemia, sickle cell disease, pediatric PK deficiency, MDS-associated anemia and phenylketonuria (PKU). In addition to its clinical pipeline, Agios is advancing a preclinical TMPRSS6 siRNA as a potential treatment for polycythemia vera. For more information, please visit the company's website at www.agios.com

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Beam Therapeutics is a biotechnology company committed to establishing the leading, fully integrated platform for precision genetic medicines. To achieve this vision, Beam has assembled a platform that includes a suite of gene editing and delivery technologies and is in the process of building internal manufacturing capabilities. Beam's suite of gene editing technologies is anchored by base editing, a proprietary technology that is designed to enable precise, predictable and efficient single base changes, at targeted genomic sequences, without making double-stranded breaks in the DNA. This has the potential to enable a wide range of potential therapeutic editing strategies that Beam is using to advance a diversified portfolio of base editing programs. Beam is a values-driven organization committed to its people, cutting-edge science, and a vision of providing life-long cures to patients suffering from serious diseases.

BridgeBio is a commercial-stage biopharmaceutical company founded to discover, create, test and deliver transformative medicines to treat patients who suffer from genetic diseases and cancers with clear genetic drivers. BridgeBio's pipeline of development programs ranges from early science to advanced clinical trials. BridgeBio was founded in 2015 and its team of experienced drug discoverers, developers and innovators are committed to applying advances in genetic medicine to help patients as quickly as possible.

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GUIDING PRECISION MEDICINE

Centogene is a leading company in the field of genetic diagnostics and precision medicine, dedicated to transforming clinical, genetic, and biochemical data into medical solutions for patients. Based in Rostock, Germany, the company operates globally.

Founded in 2006 with the mission of revolutionizing the diagnosis of rare diseases, Centogene has since scaled its capabilities to diagnose more than 2,500 rare diseases in over 100 countries, building one of the largest genetic databases in the world (1,000,000 individuals) while developing cutting-edge technology for the interpretation of genetic data. With over 350 scientific publications, Centogene is a key partner for physicians in rapid and accurate genetic diagnosis, and for pharmaceutical companies focused on developing treatments for orphan diseases.

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FOUNDATION FOR
ANGELMAN SYNDROME
THERAPEUTICS

FAST is the premier patient advocacy organization working to cure Angelman syndrome. As the largest funder of Angelman syndrome research in the world, our goal is to drive forward transformative research and development programs as quickly as possible for those living with Angelman syndrome – regardless of age or genotype.

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NewBridge Pharmaceuticals, headquartered in Dubai, UAE, is a regional specialty company with a comprehensive pharmaceutical platform of services and expertise, established to bridge the access gap and partner with global pharma and biotech companies to in-license and commercialize U.S. FDA or EMA approved innovative therapeutics that address unmet medical needs into the Middle East and North Africa (MENA) regions.

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We are an innovative global healthcare company, driven by one purpose: we chase the miracles of science to improve people's lives.

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Vector Pharma is a full service distributor in the Middle East, North Africa & Turkey region, with a focus on Rare Disease and Oncology. Incorporated in 2019, Vector Pharma was born out of the combination of industry experts and local distributor know how. Our skill set focuses on demand generation, and payor access while upholding the highest ethical and compliance standards in operating our business. To learn more about us, visit: www.vectorpharma.me Vector Pharma is a member of the World Orphan Drug Alliance (WODA). WODA provides full-service solution to pharmaceutical & biotech companies with a portfolio of rare diseases, oncology and highly specialized therapeutics, starting from named patient programs to full commercialization. Visit us at https://www.woda-alliance.com WODA covers 156 countries in the following regions: - Central and Eastern Europe- Latin America - Middle East, North Africa & Turkey - Russia & the CIS region- Switzerland – Israel – SE Asia & ANZ – Japan & South Korea -Africa

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1. **From Diagnosis to Daily Life: The Quality of Life in MarfanSyndrome**
   Hagar M. Aly
2. **Adrenocortical Carcinoma: A Case Series at a UAE Tertiary Care Hospital**
   Ahmed Ali
3. **The Enigma of West Syndrome: A Case of Infantile Spasms Without Genetic Clues**
   Ali Raafat Ammar
4. **Unveiling the Epigenetics of Rare Autoimmune Diseases: A Path Toward miRNA-Targeting Therapies**
   Amina Toumi
5. **Exploring the clinical, neuroimaging, and genetic spectrum of PLPBP deficiency: multicenter case series and systematic review**
   Brahim Tabarki Melaiki
6. **Exploring the clinical, genetic spectrum and treatment options of TANGO2 deficiency: multicenter case series from the Gulf region and systematic review**
   Brahim Tabarki Melaiki
7. **Treatment of Arnold Chiari Malformation patients using RAMPA therapy: Craniomaxillofacial growth guidance method**
   Bumkyoo Choi
8. **Treatment of Down syndrome patients using RAMPA therapy: Craniomaxillofacial growth guidance method**
   Yuko Kojima
9. **Treatment of Antley-Bixler patients using RAMPA therapy: Craniomaxillofacial growth guidance method**
   Yasushi Mitani
10. **Evaluating the Impact of Nitisinone on Disease Progression in Alkaptonuria: A Systematic Review and Meta-Analysis of Efficacy and Safety**
    Ekram Hassan Hasanin
11. **Machine Learning Application in Autoimmune Skin Diseases: State of Art and Future Prospects**
    Hagar M. Aly
12. **AN UNCOMMON PRESENTATION OF A VERY COMMON DISEASE- THE ULTIMATE MASQUERADER**
    Janso Kollanur
13. **Nono associated X-linked intellectual disability syndrome**
    Kuldeep Dhariwal
14. **Clinical Insights into SPTBN4 Disorder**
    Lana Khaled Mashal
15. **The Automation of Clinical Genetic Data through Implementation of ACMG guidelines**
    Mariam Eldesouky
16. **Clinical Presentation Of Intracranial Melanotic Schwannoma**
    Mohamed A Elzoghby
17. **From Persistent Cough to Psychogenic Diagnosis: A Case Report in a Teenage Patient**
    Mohammad Raed Alghzawi

18. **Novel presentation of pulmonary siderosis in welder worker: A case report**
    Mohammad Tariq Al Fakeeh
19 **LET'S SEE IT TOGETHER A Rare Case Presentation of Dysmorphology**
    Mohnish Darshan
20. **Desmoplastic Small Round Cell Tumour: Single Institution Case Series in the Middle East and North Africa Region**
    Nouran Alkhoori
21. **Diagnostic and Surgical Challenges in Extradigital Glomus Tumor: A Case Report**
    Priya Rani
22. **A Rare Case of Transmesocolic Hernia in an Adult - A Case Report**
    Sabira Morbiwala
23. **RDx: A Comprehensive AI-Driven Platform for Rare Disease Diagnosis and Management**
    Sameer Malik
24. **Reducing global health inequalities for the rare neurodevelopmental condition, Prader-Willi Syndrome (PWS): the role of the International PWS Organisation.**
    Prof. Tony Holland
25. **Reversing Acute Cardiomyopathy with Coenzyme Q10 supplementation in Cobalamin B Disease: A Case Report and literature review**
    Dalia Ra'A Ahmed Said
26. **Penetrating Non Missile Head injuries – Phineas Gage Revisited!!!**
    Prof Dr Pramod Giri
27. **THE IMPACT OF YASMIN ELSAMRA FOUNDATION DEBRA EGYPT ON EPIDERMOLYSIS BULLOSA PATIENTS IN EGYPT**
    Hanaa Elsadat
28. **Case Report: A novel mutation of Idursulfatase gene in a Libyan child with a mucopolysaccharidosis type II**
    Maryem Ismail
29. **Case series: Genotype-Phenotype Correlation in Niemann-Pick Disease Types A, B, and Intermediate Variants: Diagnostic and Therapeutic Insights from a Libyan Family**
    Maryem Ismail
30. **Prepaire's iRDKG: Accelerating Drug Repurposing for Rare Diseases Through Integrated Knowledge Graphs**
    Archana Krishna Kumar
31. **Clinical Characteristic and Outcomes of C3 Glomerulopathy – Single Centre Experience**
    Fatima Alkindi
32. **Incremental Use of Albumen Along With Fresh Frozen Plasma in Therapeutic Plasma Exchange For Acquired Thrombotic Thrombocytopenic Purpura**
    Nihal Bashir
33. **Autistic Traits in Rett Syndrome: A Meta-Analysis**
    Joman Alshereida

Floor Plan


STAGE 11x3
CONCURRENT SESSION: ALTHURAYA BALLROOM A
STAGE 13x3
CONCURRENT SESSION: ALTHURAYA BALLROOM B
CONCURRENT SESSION: ALTHURAYA BALLROOM C
MAIN TRACK: ALTHURAYA BALLROOM
ENTRANCE
EXIT
EXIT
ENTRANCE
Networking Zone
Poster Exhibition
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TV
PROJECTOR
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