Day 1: Thursday, 17 April 2025

Scientific Main Track: Al Thuraya A&B

Opening Session

Chairperson: Prof. Ayman El-Hattab

09:00	Opening remarks: MENA Congress for Rare Diseases	Prof. Ayman El-Hattab
09:10	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	Panel Discussion	Dr. Jennifer Jackson Ms. Alexandra Heumber Perry Dr. Soraya Bekkali Dr. Zahra Alsahlawi
10:00	Opening ceremony and award distribution	
10:30	Coffee Break	

Satellite Symposium: Al Thuraya B

1st MENA Summit for Gene and Cell Therapy

Chairperson: Dr. Nameer Al-Saadawi

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

Satellite Symposium: Al Thuraya B

1st MENA Summit for Hemoglobinopathies

Chairperson: Prof. Khaled Musallam

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

Satellite Symposium: Al Thuraya A

1st MENA Summit for the Limb Girdle Muscular Dystrophies

Chairperson: Prof. Nicholas Johnson

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

Satellite Symposium: Al Thuraya A

1st MENA Summit for Autism and Neurodivergence

Chairperson: Ms. Tanuka Gupta

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

Satellite Symposium: Al Thuraya A

1st MENA Summit for Inclusion and Diversity

Chairperson: Mrs. Renate Baur-Richter

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

Satellite Symposium: Al Thuraya C

2nd MENA Summit for Genetic Counselors - Part 1

Chairperson: Dr. Muna Al Saffar

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

Satellite Symposium: Al Thuraya C

2nd MENA Summit for Genetic Counselors - Part 2

Chairperson: Mr. Rifaat Rawashdeh

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

برنامج تدريبي: قاعة الثريا ج

المدرسة الحسية وبرتوكول بوب لتأهيل الحواس (اليوم الأول)

رئيس الجلسة: أ.د بهاء الدين جلال

05:30 to 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	The clinical and mutational spectrum of Bardet-Biedl syndrome in Saudi Arabia	Dr. Rola Ba-Abbad
08:50	When pediatric cataract is a sign of undiagnosed systemic disease	Prof. Arif O. Khan
09:10	Navigating retinal disorders in a pediatric ophthalmology clinic	Dr. Imran Jawaid

Scientific Concurrent Session: Al Thuraya B
Rare Malignancies
Chairperson: Dr. Hassan Jaafar

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

Community Support Session: Al Thuraya A
Psychosocial Challenges in Rare Diseases
Chairperson: Dr. Rasheed Alhammadi

08:30	Holistic and innovative approaches to psychiatric care in rare diseases	Dr. Hamid Alhaj
08:50	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	Psychiatric support for children with rare diseases: addressing developmental and emotional needs	Dr. Muhammad Tahir

Community Support Session: Al Thuraya A
Patient Advocacy for Rare Diseases
Chairperson: Mrs. Hanaa El-Sadat

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

Training Program: Al Thuraya C
Intimaa
Chairperson: Ms. Nipa Bhuptani

08:30 to 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
01:00	Lunch Break	

Scientific Main Track: Al Thuraya A&B
Keynote Presentations on Rare Diseases
Chairperson: Dr. Joanne Sadier

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

Scientific Main Track: Al Thuraya A&B
Newborn Screening and Rare Diseases
Chairperson: Prof. Osama Aldirbashi

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

Scientific Concurrent: Al Thuraya A&B
Best Practices for Management of Rare Diseases
Chairperson: Prof. Asma Deeb

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

Scientific Concurrent Session: Al Thuraya B
Rare Immune Diseases
Chairperson: Prof. Mohamed Abuzakouk

04:30	Combined immunodeficiency disorders	Dr. Hiba Shendi
04:50	Hereditary angioedema: diagnosis and novel treatment	Dr. Hamad Alhameli
05:10	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 to 05:30	Panel discussion	Dr. Bassam Darwish Dr. Abeer Al Naqbi Ms. Ramola Talwar Badam

Scientific Concurrent Session: Al Thuraya C
The knowns and the unknowns in rare diseases
Chairperson: Dr. Anwar Baban

04:30	Introduction	Dr. Anwar Baban
04:40	Anorexia Nervosa and Body Image	Prof. Haleama Al Sabbah
04:50	Rare X-linked disease: Lesch-Nyhan syndrome	Ms. Dana Hammad
05:00	Rare case of NONO-associated X-linked intellectual disability syndrome	Dr. Kuldeep Dhariwal
05:10	Case of limbic encephalitis	Dr. Himanshu Soni
05:20	Case study: Tyrosinemia type 1 or Maleylacetoacetate Isomerase deficiency? Insights from Quebec's founder effect	Dr. Farah ElTurk
05:30	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 To 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	Multidisciplinary approach to dental treatment of individuals with rare diseases	Dr. Shiamaa Almashhadani
08:50	Dental manifestations of rare diseases and their management	Dr. Ilhaam Abbas
09:10	Behavior management techniques in dentistry for people of determination	Dr. Safeya Alghareb i

Scientific Concurrent Session: Al Thuraya B
Rehabilitation for Rare Diseases
Chairperson: Dr. Binu George

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

Scientific Concurrent Session: Al Thuraya A
Pharmacoeconomics and Access to Orphan Drugs in Rare Diseases
Chairperson: Dr. Mohammad Yousuf

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

Scientific Main Track: Al Thuraya A&B
Updates on Diagnostics for Rare Diseases
Chairperson: Prof. Bassam Ali

11:00	The power of rare disease diagnostics	Dr. David Kasper
11:20	Laboratory diagnostic approach in inborn errors of metabolism	Prof. Osama Aldirbash
11:40	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	Unlocking genetic mysteries: revolutionizing rare disease diagnosis with machine learning	Dr. Imane Boudellioua

Scientific Main Track: Al Thuraya A&B
Novel Therapies for Rare Diseases
Chairperson: Prof. Jordi Surralles

02:00	Genomic medicine in Fanconi anemia: from genes to drug repurposing and advanced therapies	Prof. Jordi Surralles
02:20	Treatable metabolic and genetic disorders mimicking cerebral palsy	Prof. Brahim Tabarki Melaiki
04:00	Coffee Break	

Scientific Concurrent Session: Al Thuraya B
Nutritional Support for Rare Diseases
Chairperson: Prof. Mohamad Miqdady

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

Scientific Concurrent Session: Al Thuraya A
Insurance Coverage for Rare Diseases

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

برنامج تدريبي: قاعة الثريا ج

المدرسة الحسية وبرتوكول بوب لتأهيل الحواس (اليوم الثالث)

رئيس الجلسة: أ.د بهاء الدين جلال

05:30 to 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	Huntington in the MENA region: the way forward	Mr. Svein Olaf Olsen
08:50	Approach to chorea: steps for diagnosis	Dr. Shivam Mittal
09:10	Update on Huntington disease upcoming treatments	Prof. Pierre Krystkowiak
09:30	Human dental pulp stem cells as a therapeutic avenue for Huntington disease: the promise of NestaCell®	Prof. Rodrigo Pinheiro Araldi
09:50	Discussion	
10:30	Coffee Break	

Scientific Main Track: Al Thuraya B
Research and Innovation in Rare Diseases
Chairperson: Prof. Khaled Musallam

11:00	The role of international collaborations in rare disease research	Prof. Ali Taher
11:20	Research on rare genetic disease in UAE: challenges and opportunities	Prof. Rabih Halwani
11:40	Nuts and bolts of clinical trials in rare diseases	Prof. Shahrukh Hashmi
12:00	Abstract, 1st Place: Arab founder variants: Contributions to clinical genomics and precision medicine	Dr. Lama AlAbdi
12:10	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	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	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	Abstract, 4th Place: Voices in practice: Exploring genetic counseling ethical, cultural, social, and religious dynamics in the UAE	Ms. Hind Almarri
12:50	Abstract, 4th Place: Accurate detection of pathogenic structural variants guided by multi-platform comparison	Dr. M-Hossein Moeinzadeh
01:00	Abstract, 5th Place: BabyDetect: NBS for rare disease using tNGS – a Belgian study	Dr. Valerie Jacquemin
01:00	Lunch Break	

Disease-Specific Symposium: Al Thuraya B
3rd MENA Summit for Duchenne Muscular Dystrophy
Chairperson: Dr. Mehtab Iqbal

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

Disease-Specific Symposium: Al Thuraya A
3rd MENA Summit for Angelman Syndrome
2nd MENA Summit for Angelman Syndrome

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

قاعة الثريا أ
الملتقى الأول لدعم وإسعاد أسر الأمراض النادرة
تحت رعاية وحضور سمو الشيخة عايشة بنت عبيد بن بطي المكتوم

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

Patients & Families Meeting: Al Thuraya A
3rd MENA Rare Disease Symposium for Patients and Families
Chairperson: Dr. Khawla Al Shehhi

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

اجتماع المرضى والعائلات: (قاعة الثريا أ)
الاجتماع الثالث للأمراض النادرة في الشرق الأوسط وشمال افريقيا للمرضى وعائلاتهم
رئيس الجلسة: د. خوله الشحي

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

Patients & Families Meeting: Al Thuraya A
Connecting Voices: Experiences and Insights
Chairperson: Mrs. Rana Abu Khadra

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

Training Program: Al Thuraya C
Unified Healthcare Training
Chairperson: Mrs. Areen Abuhejleh

08:30 to 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

برنامج تدريبي: قاعة الثريا ج
المدرسة الحسية وبرتوكول بوب لتأهيل الحواس (اليوم الرابع)
رئيس الجلسة: أ.د بهاء الدين جلال

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