AGENDA

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	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. 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
01:00 - 02:00	Lunch Break	

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
01:00 - 02:00	Lunch Break	

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
04:00 - 04:30	Coffee Break	

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
04:00 - 04:30	Coffee Break	

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	برنامج تدريبي: قاعة الثريا ج **المدرسة الحسية وبرتوكول بوب لتأهيل الحواس (اليوم الأول)** رئيس الجلسة: أ.د بهاء الدين جلال		
05:50 - 06:10	Disability representation in media through a Middle Eastern lens	Ms. Noura Alblook	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			Community Support Session: Al Thuraya A **Psychosocial Challenges in Rare Diseases** Chairperson: Prof. Rasheed Alhammadi		
08:30 - 08:50	The clinical and mutational spectrum of Bardet-Biedl syndrome in Saudi Arabia	Dr. Rola Ba-Abbad	08:30 - 08:50	Holistic and innovative approaches to psychiatric care in rare diseases	Dr. Hamid Alhaj
08:50 - 09:10	When pediatric cataract is a sign of undiagnosed systemic disease	Prof. Arif O. Khan	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	Navigating retinal disorders in a pediatric ophthalmology clinic	Dr. Imran Jawaid	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			Community Support Session: Al Thuraya A **Patient Advocacy for Rare Diseases** Chairperson: Mrs. Hanaa El-Sadat		
09:30 - 09:50	Treatment approaches and implementation for mismatch repair cancer syndrome	Dr. Hassan Jaafar	09:30 - 09:50	Yasmin Elsamra Foundation: transforming lives through compassion	Mrs. Hanaa El-Sadat
09:50 - 10:10	Cardiac tumors	Dr. Anas Abu Hazeem	09:50 - 10:10	MENA organization for rare diseases: Patients in the center of care	Dr. Khedidja Hedna
10:10 - 10:30	Rare malignancies in children	Dr. Mustafa Al Baroudi	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		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	Luch 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	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

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	Behavior management techniques in dentistry for people of determination	Dr. Safeya Algharebi	09:10 - 09:30	Differential pricing and reimbursement approach for innovative medication	Dr. Adel Al Assy
Scientific Concurrent Session: Al Thuraya B **Rehabilitation for Rare Diseases** Chairperson: Dr. Binu George			09:30 - 09:50	Access to high cost medications	Prof. Mohamed Farghaly
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	09:50 - 10:10	Access to orphan drugs: what is the next step?	Dr. Gihan Elsisi
10:10 - 10:30	Sleep disturbances in children with neurodevelopmental disorders	Dr. Tarek El-Azzabi	10:10 - 10:30	Managing the access paradox: what comes first	Mr. Mohamad Rammal
10:30 - 11:00	Coffee Break		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

Chairperson: Prof. Mohamad Miqdady

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

Community Support Session: 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	

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

09:50 - 10:30	Discussion		10:00 - 10:30	جلسة حوارية	الدكتورة فداء ذياب د. رشا عبدالرحمن ألاستاذة سعاد فارس
10:30 - 11:00	Coffee Break		10:30 - 11:00	Coffee Break	
Scientific Main Track: Al Thuraya B **Research and Innovation in Rare Diseases** Chairperson: Prof. Khaled Musallam			قاعة الثريا أ **الملتقى الأول لدعم وإسعاد أسر الأمراض النادرة تحت رعاية وحضور سمو الشيخة عايشة بنت عبيد بن بطي المكتوم**		
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	11:00 - 11:05	كلمة الترحيب	الاستاذ الدكتور أيمن الحطاب
11:40 - 11:50	Abstract, 1st Place: Arab founder variants: Contributions to clinical genomics and precision medicine	Dr. Lama AlAbdi	11:05 - 11:10	كلمة الأفتتاح	سمو الشيخة عايشة بنت عبيد بن بطي المكتوم
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	11:15 - 11:20	أمهات ملهمات في مجال الأمراض النادرة	الدكتورة فداء ذياب
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	11:20 - 11:30	تكريم الأمهات الملهمات في أسر الأمراض النادرة	
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	11:30 - 11:45	لماذا نستخدم ساعة تابي أمان	الاستاذ يوسف الحسيني
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	11:45 - 12:00	تجربتي مع ساعة تابي أمان	الدكتورة فداء ذياب
12:30 - 12:40	Abstract, 4th Place: Accurate detection of pathogenic structural variants guided by multi-platform comparison	Dr. M-Hossein Moeinzadeh	12:00 - 12:15	توزيع ساعات تابي امان على أصحاب الأمراض النادرة	

12:40 - 12:50	Abstract, 5th Place: BabyDetect: NBS for rare disease using tNGS – a Belgian study	Dr. Valerie Jacquemin	12:15 - 01:00	ورشة عمل عن كيفية استعمال ساعة تابي أمان	الاستاذ يوسف الحسيني
01:00 - 02:00	Lunch Break		01:00 - 02:00	Lunch Break	
Disease-Specific Symposium: Al Thuraya B **3rd MENA Summit for Duchenne Muscular Dystrophy** Chairperson: Dr. Mehtab Iqbal			Patients & Families Meeting: Al Thuraya A **3rd MENA Rare Disease Symposium for Patients and Families** Chairperson: Dr. Khawla Al Shehhi		
02:00 - 02:30	Duchenne muscular dystrophy: an overview of manifestations and importance of early diagnosis	Dr. Mehtab Iqbal	02:00 - 02:20	Genetic diseases: inheritance and diagnosis	Dr. Heba Elabd
02:30 - 02:50	Duchenne muscular dystrophy and standards of care	Dr. Karolina Podolska	02:20 - 02:40	Acceptance and coping strategies for psychological distress: life skills for parents of people of determination	Dr. Rasha Abdelrahman
02:50 - 03:10	The Duchenne community: education and networking	Ms. Nicoletta Madia	02:40 - 03:00	The effect of nutritional interventions on rare disease	Ms. Hadeel Iraq
03:10 - 04:00	Discussion		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		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	السيـدة هـالة عبـاس
05:40 - 05:50	جرعة أمل	السيدة بدور النواجحة
05:50 - 06:00	رحلة التشخيص و بدايات رحلة الأمومة لطفل من ذوى الهمم	السيدة دعاء أبورزق
06:00 - 06:10	أنصتوا فأنا كورنيليا دي لانج	السيدة نشمية الفيلى
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 الثالث)

رئيس الجلسة: أ.د بهاء الدين جلال

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