



SCIENTIFIC AGENDA

DAY 1 – THURSDAY, 29 FEBRUARY 2024

TIME	ACTIVITY	SPEAKER
7:00 - 7:50 AM	● On-site Registration	
7:50 - 8:00 AM	● Opening Remarks	Dr. Amal Al Tenaiji
TIME	TOPIC	SPEAKER
SESSION 1: RARE DISEASES - THE BIG PICTURE		MODERATOR: PROF. MOEEN AL SAYED/DR. AMAL AL TENAIJI
8:00 - 8:30 AM	● Keynote Speech: State of the Art in Rare Disease	Dr. Marshall Summar
8:30 - 8:50 AM	● The Landscape of Rare Diseases in the UAE: Current and Future Prospectives	Dr. Fatma Al Jasmi
8:50 - 9:10 AM	● Emerging Role of Pharmacogenomics in Clinical Practice	Prof. Bassam Ali
9:10 - 9:20 AM	● Panel Discussion	Moderators
9:20 - 9:30 AM	COFFEE BREAK	
9:30 - 10:30 AM	● OFFICIAL INAUGURATION	
SESSION 2: BASIC DIAGNOSTIC APPROACHES TO RARE DISEASE		MODERATOR: PROF. ZUHAIR AL HASSNAN/DR. NOURA AL DHAHERI
10:30 - 10:50 AM	● The Golden Rules of Genetic Testing	Dr. Azza Attia
10:50 - 11:10 AM	● Biochemical Investigations: A Route to Diagnosis in Rare Disease	Dr. Hamda Abulhoul
11:10 - 11:30 AM	● Advancing the Diagnosis of Rare Disease in the Era of Genomics	Dr. Ahmed Abu Tayoun
11:30 - 11:50 AM	● Beyond the Exome: A Road to Diagnosis of the Rare and Undiagnosed Disease	Dr. Aziz Mhanni
11:50 - 12:00 PM	● Panel Discussion	Moderators
12:00 - 1:00 PM	LUNCH BREAK	
SESSION 3: TREATABLE RARE DISEASE		MODERATOR: DR. NADIA AL HASHMI/DR. NUHA AL ZAABI
1:00 - 1:20 PM	● Advances in Management of Acid Sphingomyelinase Deficiency	Dr. Hamda Abulhoul
1:20 - 1:40 PM	● Pompe Disease: New Horizons in Therapy	Dr. Amal Al Tenaiji
1:40 - 2:00 PM	● Recent insights into lysosomal acid lipase deficiency	Dr. Noura Al Dhaheri
2:00 - 2:20 PM	● Updates in the Treatment of CDKL5 Deficiency	Dr. Sunny Philip
2:20 - 2:40 PM	● Hyperphagia & Early-Onset severe Obesity: A Therapeutic Update	Dr. Asma Deeb
2:40 - 2:50 PM	● Panel Discussion	Moderators
2:50 - 3:00 PM	COFFEE BREAK	

DAY 1 – THURSDAY, 29 FEBRUARY 2024 (PARALLEL WORKSHOPS)

TIME	ACTIVITY	SPEAKER
03:00 - 05:00 PM	● Workshop 1: Skeletal Dysplasia	Dr. Asma Deeb
03:00 - 05:00 PM	● Workshop 2: Cardiomyopathy	Prof. Zuhair Al Hassnan
03:00 - 04:00 PM	● Workshop 3: Treatable Seizures: Cases & Challenges	Dr. Nuha Al Zaabi
04:00 - 05:00 PM	● Workshop 4: Genetic Cases: A Step by Step Approach	Dr. Maryam Al Shehhi

DAY 1 – THURSDAY, 29 FEBRUARY 2024 (SPECIAL WORKSHOP)

01:00 - 05:00 PM	● PhenoDb Wokshop	Dr. Nara Sobreira
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SCIENTIFIC AGENDA

DAY 2 – FRIDAY, 1 MARCH 2024

TIME	ACTIVITY	SPEAKER
07:00 - 07:50 AM	● On-site Registration	
07:50 - 08:00 AM	● Opening Remarks	Dr. Amal Al Tenaiji

TIME	TOPIC	SPEAKER
SESSION 4: FOCUS ON THERAPIES FOR RARE DISEASES		MODERATOR: DR. MARSHALL SUMMAR/DR. FATMA AL JASMI
08:00 - 08:30 AM	● Rare Disease Therapeutics in the Molecular Age	Dr. Tamanna Roshan
08:30 - 08:50 AM	● Update of Precision Therapeutics in Inborn Errors of Metabolism	Prof. Moeen Al Sayed
08:50 - 09:10 AM	● Emirati Genome: A National Enabler of Precision Medicine	Ms. Meera Juma Al Mansoori
09:10 - 09:20 AM	● Panel Discussion	Moderators

09:20 - 09:30AM COFFEE BREAK

SESSION 5: PREVENTION		MODERATOR: DR. AZZA ATTIA/DR. MARYAM AL SHEHHI
09:30 - 09:50 AM	● SEHA Research Update	Dr. Mariam Al Harbi
09:50 - 10:10 AM	● Impact of High Risk Genetic Screening and Genetic Counselling	Ms. Maria Al Hinai
10:10 - 10:30 AM	● A Comprehensive Overview of Newborn Screening: Its not Just a Test!	Dr. Noura Al Dhaheri
10:30 - 11:40 AM	● Panel Discussion: Premarital Genetic Screening	Dr. Fatma Al Jasmi and Panelists

11:30 - 11:40 AM COFFEE BREAK

SESSION 6: TREATABLE GENETICS DISORDERS: AN UPDATE		MODERATOR: DR. HIND AL SHARHAN/DR. EMAN AL SHAMSI
11:40 - 12:00 PM	● Understanding the Newest Therapeutic Advances in Neuromuscular Diseases	Dr. Maryam Al Shehhi
12:00 - 12:20 PM	● An Update on the Management of ENPP1 deficiency	Prof. Zulf Mughal

12:20 - 01:20 PM LUNCH & FRIDAY PRAYER BREAK

01:20 - 01:40 PM	● A Treatable cause of Megaloblastic Anemia: Hereditary Orotic Aciduria	Dr. Amal Al Tenaiji
01:40 - 02:00 PM	● A Treatable cause of Hearing Loss: Alpha-mannosidosis	Dr. Fatma Al Jasmi
02:00 - 02:20 PM	● Episodic Ataxia: Update on Therapy	Prof. Mauro Pessia
02:20 - 02:40 PM	● Early Awareness and Diagnosis of Mucopolysaccharidosis	Dr. Amal Al Tenaiji
02:40 - 02:50 PM	● Panel Discussion	Moderators

02:50 - 03:00 PM COFFEE BREAK

DAY 2 – FRIDAY, 1 MARCH 2024 (PARALLEL WORKSHOPS)

TIME	ACTIVITY	SPEAKER
03:00 - 05:00 PM	● Workshop 1: Prenatal Genetic Screening	Prof. Hisham Mirghani Dr. Nadia Al Hashimi
03:00 - 05:00 PM	● Workshop 2: Genetic Counseling 101	Dr. Muna Al Saffar
03:00 - 04:00 PM	● Workshop 3: Clinical Approach to Developmental Delay	Dr. Hind Al Sharhan
04:00 - 05:00 PM	● Workshop 4: Hemoglobin Electrophoresis Made Easy	Dr. Eman Al Shamsi

DAY 2 – FRIDAY, 01 MARCH 2024 (SPECIAL WORKSHOP)

01:00 - 05:00 PM	● PhenoDb Wokshop	Dr. Nara Sobreira
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FAMILY DAY AGENDA

DAY 3- SATURDAY, 2 MARCH 2024

TIME	ACTIVITY	SPEAKER
9:00 AM	● Quran Kareem قرآن كريم	Mr.Mohamed Nasser Alkhaja
9:05 AM	● Welcome massage	Mrs. Nafisa Tawfiq

TIME	TOPIC	SPEAKER
SESSION 1: QUALITY LIFE OF THE RARE جودة حياة النادر MODERATOR: DR. EMAN AL SHAMSI / MRS. NAFISA TAWFIQ		
9:10 AM	● Discussion Session About Support of Special Categories جلسة حوارية عن دعم الفئات الخاصة	Dr.Younis Kazim Dubai Health Authority Ms. Amna Alremeithi Ministry of Health and Prevention Mr. Salem Bin Lahej - Ms.Hajer Al Ali Al Jalila Foundation Dr. Mahmoud Alshathily Zayed Higher Organization for People of Determination

10:40 AM COFFEE BREAK

10:55 AM	● Hero's Creation 1 إبداعات الإبطال	Ms.Esra Ali Yousef
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SESSION 2: MY THERAPIST AND I معالجي وأنا MODERATOR : DR. AZHAR TALAL – MRS.MAHA ALKAABI		
11:00 AM	● Rehabilitation التأهيل	Dr. Mohammed Naser Abdulwahid Mrs. Muna Alshamsi
11:20 AM	● Therapeutic Nutrition التغذية العلاجية	Ms. Masooma AlJasmi - Mrs. Monique Lynch - Mr.Rashed Al Zaabi
11:40 AM	● Rare Case (Physician and Patient) حالة نادرة (طبيب ومريض)	Dr. Norah AlSaleh - Mr. Ameen Adnan Almeslimani
12:00 PM	● Neurofibrosis and its effect on the growth and development of the child التليف العصبي وتأثيره على نمو وتطور الطفل	Dr. Hibba Bedri - Abu Mohammed Family

12:20 PM LUNCH BREAK

13:20 PM	● Hero's Creation 2 إبداعات الإبطال ٢	Ms. Salama Alblooshi
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SESSION 3: SUPPORT AND SERVICES FOR RARE الدعم والخدمات للفئة النادرة MODERATOR: MRS. NAFISA TAWFIQ		
13:25 PM	● Emirates program services of early intervention خدمات برنامج الإمارات للتدخل المبكر	Ms. Maryam Al shehhi Ministry of Community Development
13:40 PM	● Rehabilitation services in POD governmental Centres خدمة التأهيل بمراكز أصحاب الهمم الحكومية	Ms. Abeer Rashid Alshehhi Ministry of Community Development
13:55 PM	● Integrated Case Management in the Family Care Authority إدارة الحالة المتكاملة في هيئة الرعاية الأسرية	Dr. Dana Al Marzooqi Family Care Authority
14:05 PM	● Cabability Research Center services خدمات مركز الموارد لذوي الإعاقة	Dr. Ahmed Falah Al Amoosh Al sharjah University
14:15 PM	● Deviating from the linear roadmap in management of Rare disease التخفيف عن خارطة الطريق المستقيمة في إدارة الأمراض النادرة	Ms. Alaa Fahmi Axios International
14:25 PM	● Hero's Creation 3 إبداعات الإبطال ٣	RD Hero

SESSION 4: أنا متميز (أين كنت وأين أصبحت) - قصص وتجارب MODERATOR : MS. DALAL AL DHABYANI - MS. SALAMA AL NUAIMI		
14:30 PM	● The journey of the impossible. From challenge to achievement رحلة اللامستحيل..من التحدي للإنجاز	Ms. Raisa Al Falasi
14:40 PM	● Living with Invisible Disease التعايش مع الأمراض النادرة الخفية	Ms. Alia Al Mulla
14:50 PM	● My story with the butterfly قصتي مع الفراشة	Ms. Abrar Alothman



FAMILY DAY AGENDA

DAY 3- SATURDAY, 2 MARCH 2024

15:00 PM	● Be a member	كن عضواً	Ms. Dalal Al Dhabyani
15:10 PM	COFFEE BREAK		
TIME	TOPIC		SPEAKER
SESSION 5: DISCUSSION SESSION ABOUT FERTILITY		الوقاية بالخصاب	MODERATOR : DR. NUHA ALZAABI
15:30 PM	● Discussion Session		Dr. Mohamed Elkalyoubi Dubai Fertility Center
16:30 PM	● Q&A Session		
16:45 PM	● Closing Remarks		Mrs. Nafisa Tawfiq

DAY 3 - SATURDAY, 2 MARCH , 2024 (PARALLEL WORKSHOPS)

TIME	ACTIVITY	SPEAKER
17:00 PM	● Supporting the caregivers, addressing issues and challenges of daily life التعامل مع تفاصيل التحديات اليومية ، ورشة عمل للعائلات	Dr. Leena Amiri Mrs. Sharifa Yateem

