

# جمعية الإمارات للأمراض الجينية UAE GENETIC DISEASES ASSOCIATION

EDUCATE . NURTURE . PREVENT



مركز الشيخ زايد للأبحاث الجينية  
SHEIKH ZAYED GENETIC RESEARCH CENTER



جمعية الإمارات للأمراض الجينية  
UAE GENETIC DISEASES ASSOCIATION

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UAE GDA and Sheikh Zayed Research Centre were founded in 2004 as a dedication to the memory of His Highness Sheikh Zayed bin Sultan Al Nahyan, founding father of the U.A.E.



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تثقيف · تهيئة · وقاية

## **Our Vision**

**To Pioneer in preventive and screening program for common disorders in UAE and the region.**

## **Our Mission**

- To understand the Biochemical and molecular basis of common disorders through implementation of preventive, screening and public awareness program.**
- To promote and initiate cutting-edge research and knowledge exchange by using most innovative and cost-effective technologies.**
- To initiate and advocate for capacity building programs.**



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## HH Sheikh Nahyan Bin Mubarak Al Nahyan

- Cabinet Member and Minister of State for Tolerance of UAE
- President, UAE Genetic Diseases Association



The core volunteer team of year 2005 on the footsteps of GDA office



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## **His Highness Sheikh Mohammed bin Rashid Al Maktoum**

**Vice President and Prime Minister of the United Arab Emirates and ruler of Dubai  
inaugurated Sheikh Zayed Research Centre in March 2007**

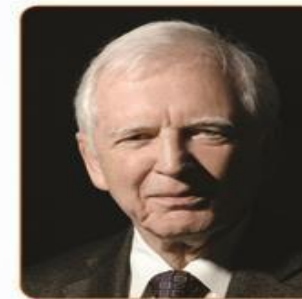


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## Noble laureates Support and Recognise the Community Empowerment Initiatives by UAE GDA



Harald zur Hauser



Jean-Marie Lehn



Ferid Murad



Michel Hartmut



Robert Huber

In 2012, UAE GDA received a massive vote of support from Noble Laureates who visited our facility as part of their global tour to identify best practices in healthcare.

**“UAE GDA is a spot of light in Arab world”**

was the message of these esteemed scientists

Pioneering the advocacy and awareness on genetic screening and prevention of genetic disorders in UAE

## Since Founding UAE GDA in 2004, we have achieved:

- Legislation on Mandatory Premarital screening
- Legislation on Mandatory Newborn screening
- A national screening program for the common genetic blood disorders in 2006 aimed at identifying Thalassemia, Sickle cell anemia and G6PDH carriers in the UAE population. The largest population screening program till date in the UAE
- Manal – Folic Acid prevention program & WHO fortified wheat campaign
- A recent cabinet decision that rules that unmarried women and couples can now freeze their eggs in the UAE.
- Legislation on ban of smoking in public places in UAE



# UAEGDA MileStones

**2001**

## **Community Outreach Program**

Blood Screening for genetic disorders  
1114 students at Dubai Women's College

**2003-2014**

UAE Free of Newly Born  
Thalassemia Campaign

**2005**

Legislation of Premarital Screening  
made mandatory

**2007**

Inauguration of Sheikh Zayed Research Centre  
by His Highness Sheikh Mohammed bin Rashid  
Al Maktoum

**2009**

Introduced popular screening program for  
Hemoglobinopathies.  
Launched the **1<sup>st</sup> edition of the annual  
International Genetic Conference**

**2010**

Arabic Magazine on Genetics - Nawah

**2011**

Folic Acid Deficiency Campaign

**2012**

Nobel laureates visit UAE GDA  
Ebtisam Society and Cancer patients support  
group



**2016**

## **UAE Rare Diseases Support Groups**

Rare Diseases Excellence Awards  
GCC Genomics Society Partnership  
with Saudi Genome Project

**Launch of Alzheimer's Support Group**  
**6<sup>th</sup> International Annual Genetic  
Conference and Awards**

**2017**

Vitamin D deficiency campaign  
Fragile-X Chromosome  
Research

## **Familial hypercholesterolemia**

Research for Non-communicable  
Diseases Alliance

**2018**

Membership of Global Commission of  
Rare Diseases  
The 7<sup>th</sup> Conference and Awards

**2019**

Lead and Preparing the judging  
committee for the Arab Health  
Exhibition and Conference  
Membership of the Global Stem Cell  
Committee

**2020**

UAE Stem cell society  
UAE Research Society  
UAE Public Health  
Society





# UAEGDA MileStones

## 2022

Collaboration with Emirates Scholar Research Center

Strategic partnership for Middle East NNEdPro Network events

## 2023

Collaboration MENA Organization for Rare Diseases

## 2024

World Summit for Clinical Chemistry and Laboratory Medicine in collaboration with the Saudi Society for Clinical Chemistry, and the Arab Federation for Clinical Biology.





# UAEGDA BOARD MEMBERS

<b>Name</b>	<b>Position</b>
<b>Dr. Mariam Mohamed Matar</b>	<b>Chairperson of Board of Directors</b>
<b>Tariq Al Gurg</b>	<b>Vice President</b>
<b>Shaikha Al Mutawa</b>	<b>General Secretary</b>
<b>Faheema Mohammad Ali</b>	<b>Cashier</b>
<b>Jassem Al Blooshi</b>	<b>Board Member</b>
<b>Saeed Al Suwaidi</b>	<b>Board Member</b>
<b>Dr. Sumaya Al Blooshi</b>	<b>Board Member</b>
<b>Zainab Rashid Al Kaabi</b>	<b>Board Member</b>
<b>Dr Sheikha Al Mazrouie</b>	<b>Board Member</b>

# Scientific Committee Members (Local)



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**Dr. Mohamed Al-Sayegh**  
Research Assistant Professor  
(Research Fellow) Biology  
Division, New York University  
Abu Dhabi (NYUAD), UAE

**Dr. M Azzam Kayasseh**  
Specialist Gastroenterologist,  
Dr. Kayasseh Medical Clinic,  
Dubai, UAE

**Dr. Nishi Singh**  
MD, MS, FRCPath, FIMSA  
Consultant Medical Microbiologist-  
Virologist. Conceive Gynecology &  
Fertility Hospital. UAE  
ex-Chair, Health Sciences, Dubai  
Higher Colleges of Technology,  
Govt of UAE

**Dr. Abdullah Al Ali**  
Consultant, Zayed Military Hospital,  
UAE Geriatric Medicine & Chairman  
- Scientific Committee, Abu Dhabi  
Geriatric Conference

**Dr. Aysha Ali Al Mehri**  
President, Emirates  
Nursing Association, UAE

**Dr. Fahem Al Nuaimi**  
CEO, Ankabut UAE

**Dr. Hafez Ahmed**, PhD, MB BCh,  
MSc, Dip-RCPATH (Chemical  
Pathology, UK)  
Professor of Biochemistry at  
Dubai Medical College, Dubai,  
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**Dr. Karam Adnan Fadhli**  
Integrative Consultant  
Psychiatrist Dubai, UAE

**Dr. Fatima Al Anouti**  
Assistant Dean for Student  
Affairs, College of Natural  
and Health Sciences, Zayed  
University, UAE

**Dr. Gowri Ramanathan**  
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King's College Hospital  
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**Dr. Ibrahim Hachim**  
Member of the Teaching and  
Examination Committee,  
RAK Medical University,  
UAE

**Dr. Kamal Khazanehdari**  
Head of Molecular Biology  
and Genetics, Central  
Veterinary Research  
Laboratory

# Scientific Committee Members (Local)

## **Dr. Erol Baysal**

Consultant & Head of  
Molecular Genetics, Genetics  
Center Department of  
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Consultant, Non communicable  
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## **Dr. Fatme Al Anouti**

Associate Professor, College of  
Natural and Health Sciences,  
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## **Dr. Sara Sorrell**

Physician, Medical  
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Cleveland Clinic Abu Dhabi

## **Dr. Kanakkande Aabideen**

Consultants, Pediatric  
Hematology Oncology at Tawam  
Hospital, Al Ain, UAE

## **Dr. Amir Khan**

Stem cell Member, Assistant  
Professor at University of Sharjah  
Sharjah, UAE

## **Dr. Sheikha Al Mazrouie**

Lead Head of Stem Cells Group  
Dubai, UAE

## **Dr. Khaled Mussallam**

Group Chief Research Officer, VPS  
Healthcare Global Medical Lead  
AMICULUM, Dubai, UAE

## **Dr. Fatma Al Hashimi**

Director  
Hortman Stem Cell Laboratory  
Dubai, UAE

## **Dr. Wafaa Ayesb**

Clinical Nutritionist  
Dubai, UAE

## **Mr. Patrick Moloney**

CEO and Founder of P4ML  
Dubai, UAE

## **Dr. Awni Hawamdeh**

Managing Director of Pulse  
International FZ-LLC, Dubai, UAE

## **Dr. Yahia Kiwan**

Consultant Cardiologist  
Dubai, UAE

## **Dr. Sana Farid**

General Surgeon, Pioneer XR  
Training Expert, Lead  
Representative of Google  
ARVR and Ai, Trainer at  
Ministry of Education UAE-  
Immersive Learning

# Scientific Committee Members (Local)

**Dr. Mahmoud Marashi**  
Consultant Hematologist,  
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UAE

**Dr. Mahmoud Yaseen Hachim**  
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UAE

**Dr. Majd Dameh**  
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UAE

**Prof. Shefa Mostafa Gawish**  
M.B.B.Ch., M.Sc., PhD.  
(Anatomy) Assiut University,  
Egypt  
Professor of Anatomy, Dubai  
Medical College, Dubai, UAE -  
since 2005

**Mr. Wail Al Samawi**  
CEO, Dow Diagnostics FZ-LLC

**Dr. Mohadditha Al Hashimi**  
Director & Executive Dean, Health  
Science Programs, Sharjah  
Women's College at Higher  
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**Dr. Rawad Abou Assaleh**  
Pharmacist, Independent  
Consultant

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**Dr. Taif Sabah Al Sarraj**  
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Tawam Hospital, Al Ain, UAE

**Dr. Yousef Nazzal** Co-Chair  
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**Dr. Ibtihal Fadhli**  
Board Member, Global  
NCD Alliance

**Dr. Youssef Idaghour**  
Assistant Professor of Biology,  
Biology Department Division of  
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Abu Dhabi (NYUAD), UAE

**Dr. Saba Habibollah (MD, MSc,  
PhD)**  
Clinical Scientist (Genetics)  
Head of Education,  
Development and Quality  
Improvement Iranian Hospital,  
UAE

# Scientific Committee Members (Regional)

**Dr. Hamad M. Ali Yaseen**  
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Dasman  
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**Dr. Khaldoun Al-Romaih**  
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Specialist Hospital and  
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**Dr. Ghazi Omar Tadmouri**  
Dean of the Faculty of Public  
Health, Jinan University,  
Lebanon

**Dr. Safouq Al  
Shammary**

Arabian Gulf University,  
Bahrain

**Dr. Maarof Bin Haja Mohideen**  
Lead Consultant Obstetrician,  
Gynaecologist and  
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**Dr. Sultan Al Sedairy**  
Saudi Arabian Genome Project  
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Faisal Specialist Hospital and  
Research Center, KSA

**Prof. Abdulrahman AAlrajhi**  
Professor & Executive Director,  
Department of Medicine,  
Alfaisal University, KSA

**Dr. Hani Choudhry**  
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**Dr. Musallam S. Al- Aرامي**  
Clinical & Molecular Geneticist,  
National Genetic Centre  
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Oman

**Dr. Rami Mahfouz**  
Director, HLA and Molecular  
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of Beirut Medical Center

**Dr. Tarek Mostafa Kamal**  
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Ain Shams University, Egypt

**Dr. Maha Almozaini**  
Senior Scientist & Director of  
Immunocompromised Host  
Research (ICH), King Faisal  
Specialist Hospital and  
Research Center, KSA

**Dr. Moiz Bakheit**  
Professor and Chairman, CMMS  
–  
Arabian Gulf University Inherited  
Disorders, Bahrain

**Prof. Sami Al Qarawi**  
Professor, King Abdulla  
University of Science &  
Technology, KSA

**Dr. Hani Abdullah Alhadrami**  
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Medical Biotechnology, King  
Fahad Medical Research Center

# Scientific Committee Members (Regional)

## **Dr Maha Almozaini**

Senior Scientist & Director of Immunocompromised Host Research (ICH), King Faisal Specialist Hospital and Research Center, KSA

## **Dr. Maryam Al Shehi**

Geneticist and Pediatrician with the Royal Hospital, MOH of Oman Acting Director of the national Genetic Center at Oman and Associate Program Director of Pediatrics Residency of the Oman Medical Specialty Board Vice President and Co-Founder of the Oman Genetic Medicine Association, Oman

## **Dr. Sami Al Garawi**

Professor, King Abdulla University of Science & Technology, KSA

## **Dr. Asim Abdulaziz Khogeer**

Research and Scientific Committee Coordinator at Ministry of Health Saudi Arabia IRB Member and Scientific Reviewer, Saudi Arabia

## **Dr. Sofyan Maghaydah**

Saudi Arabian Genome Project and Executive Director, King Faisal Specialist Hospital and Research Center, KSA

## **Prof. Tawfik A. M. Khoja**

Family & Community Physician Consultant  
Professor of Public Health (Imperial College - London)  
BBBS, DPHC, FRCGP, FFPH, FRCP(UK)  
Secretary General of Arab Hospital Federation, KSA

# Scientific Committee Members (International)



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## **Prof. Ahmed Ahmed**

Professor of Gynaecological Oncology, MRC Senior Clinical Research Fellow, Weatherall Institute of Molecular Medicine (WIMM), University of Oxford

## **Dr. Alireza Haghighi**

Clinician Scientist, Department of Genetics and Medicine, Harvard Medical School and Brigham and Women's Hospital

## **Dr. Jon Andoni**

**Urtizberea** Head, Summer School of Myology, Paris, France

## **Dr. Yukio Hattori**

Professor, Yamaguchi University, Japan

## **Dr. Hosam Zowawi**

Associate Professor, University of Queensland, Australia and King Saud bin Abdulaziz University for Health Sciences, KSA

## **Prof. Firouz Darroudi**

Senior Research Consultant, IAEA (Vienna), WHO (Geneva) UNESCO (Paris) Director, Global Harmonization Initiative Platform in Genetic Toxicology

## **Dr. Manjula Anagani**

Visiting Laparoscopic Surgeon, NMC Hospitals, Dubai Maxcure Suyosha Hospital, India

## **Dr. B.R. Lakshmi,**

Founder trustee and Managing Director, Molecular Diagnostics, India

## **Dr. Peter R. Brindsen**

Consultant Medical Director, Bourn Hall Clinic, Cambridge, UK

## **Dr. Philippe Macaire**

Director of Anaesthesiology and Pain, VinMec International University Hospital

## **Dr. Marshall L.**

**Summar** Chairman, National Organisation for Rare Disorders, USA

**Dr. Majlinda Lako** PhD, Prof. of Stem Cell Sciences

Biosciences Institute Faculty of Medical Sciences Newcastle University United Kingdom



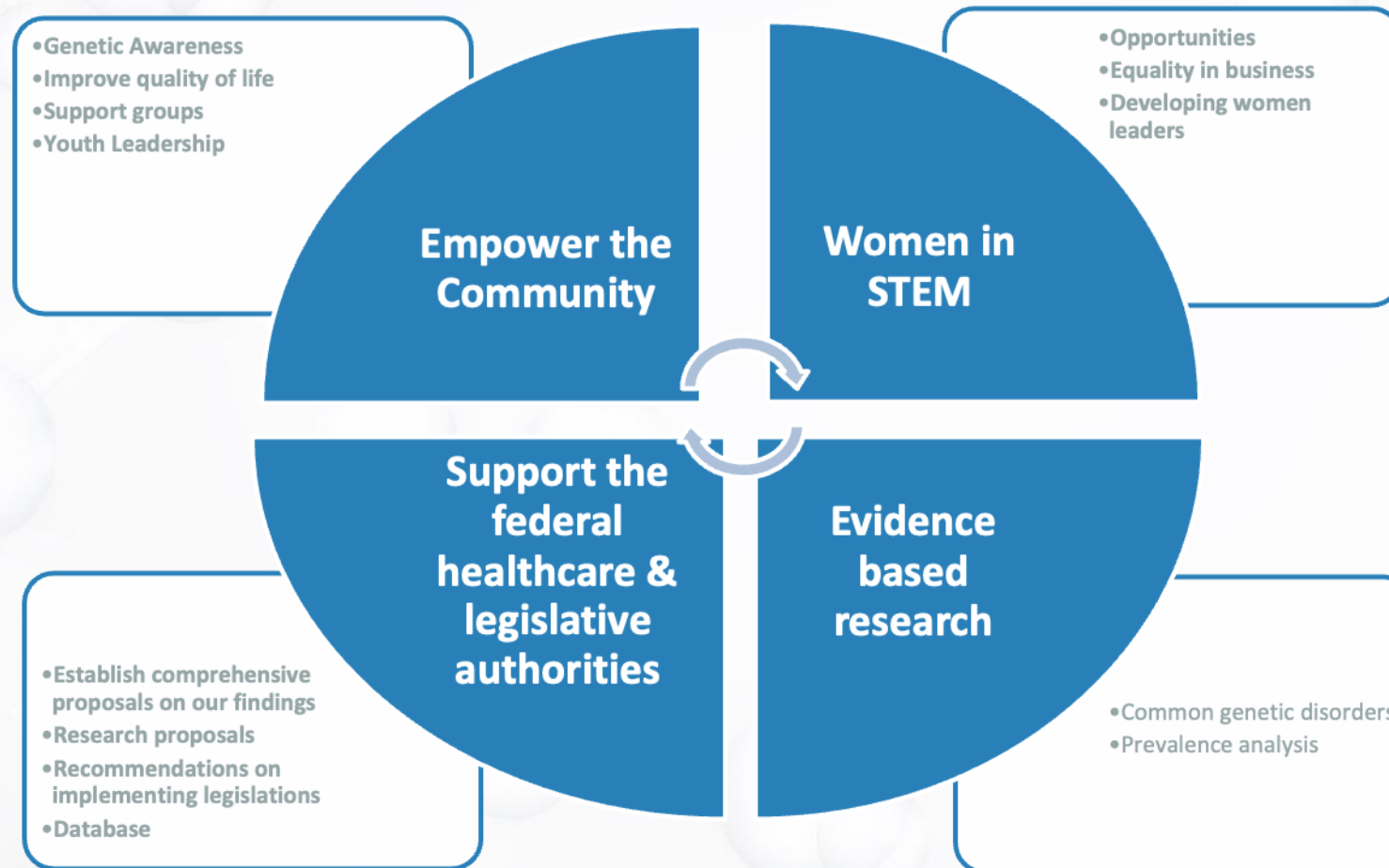


## UAEGDA Objectives

- Increase awareness of the common genetic disorders in the UAE and the region
- Empowering the community with reliable, credible and easy-to-use information about the common genetic disorders, especially preventable disorders and share the tools and services which are:
  - Available
  - Affordable
  - Accessible
- Promote “Women in STEM” through action-led and sustained programs and initiatives
- Establish comprehensive proposals on new findings which support/recommend
  - A) New Legislations
  - B) Human Resources Requirements
  - C) Education curriculum across the nation.
- Establish a reference database of genetic disorders on evidence-based research conducted in collaboration with our regional and international research partners.



# UAE GDA Objectives



## UAE GDA Goals and Pillars of Activities

- Goal 1: Foster partnerships and coordination of genetic activities within and outside of GCC region to promote health and promote prevention and screening
- Goal 2: Provide timely and accurate information to both the general public and professional audiences on the role of genetics in the promotion of health and the prevention of disease and disability.
- Goal 3: UAE GDA is committed to increasing access to genetic screening and genetic counselling for all patients, families and support groups in genetic disorders/rare diseases.
- Goal 4: Ensure the appropriateness and quality of population-based genetic testing.
- Goal 5: Establish UAE – Global knowledge exchange and bring leading global advocacy, research organisations in UAE with sustainable partnerships

## UAE GDA Goals and Pillars of Activities

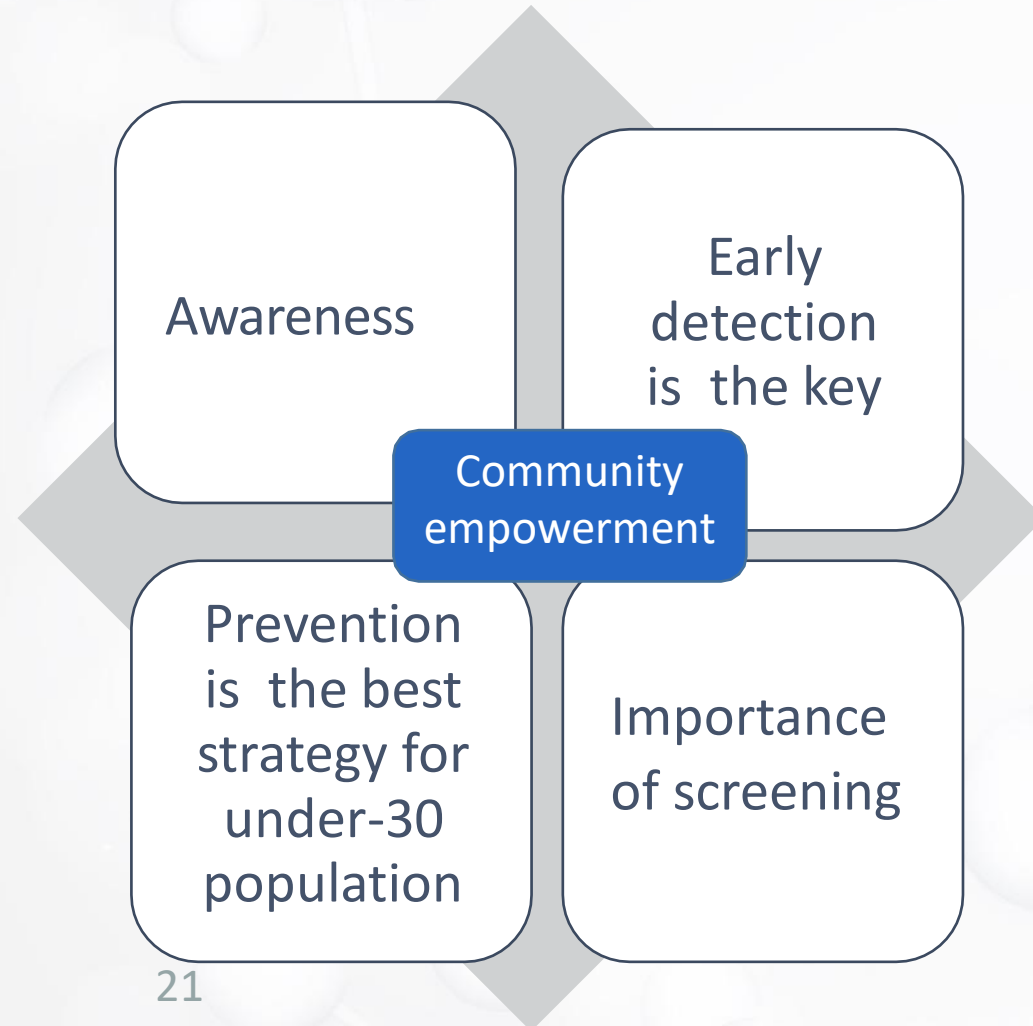
Goal 6: Nation wide Awareness & Education (& Support Global Campaigns and Events)

Goal 7: Create Scientific Learning Opportunities for local youth to become more productive citizens and support the national economy via

- Learning events
- New Research Projects
- Collaboration on training and development programs



## Community empowerment at core of our work



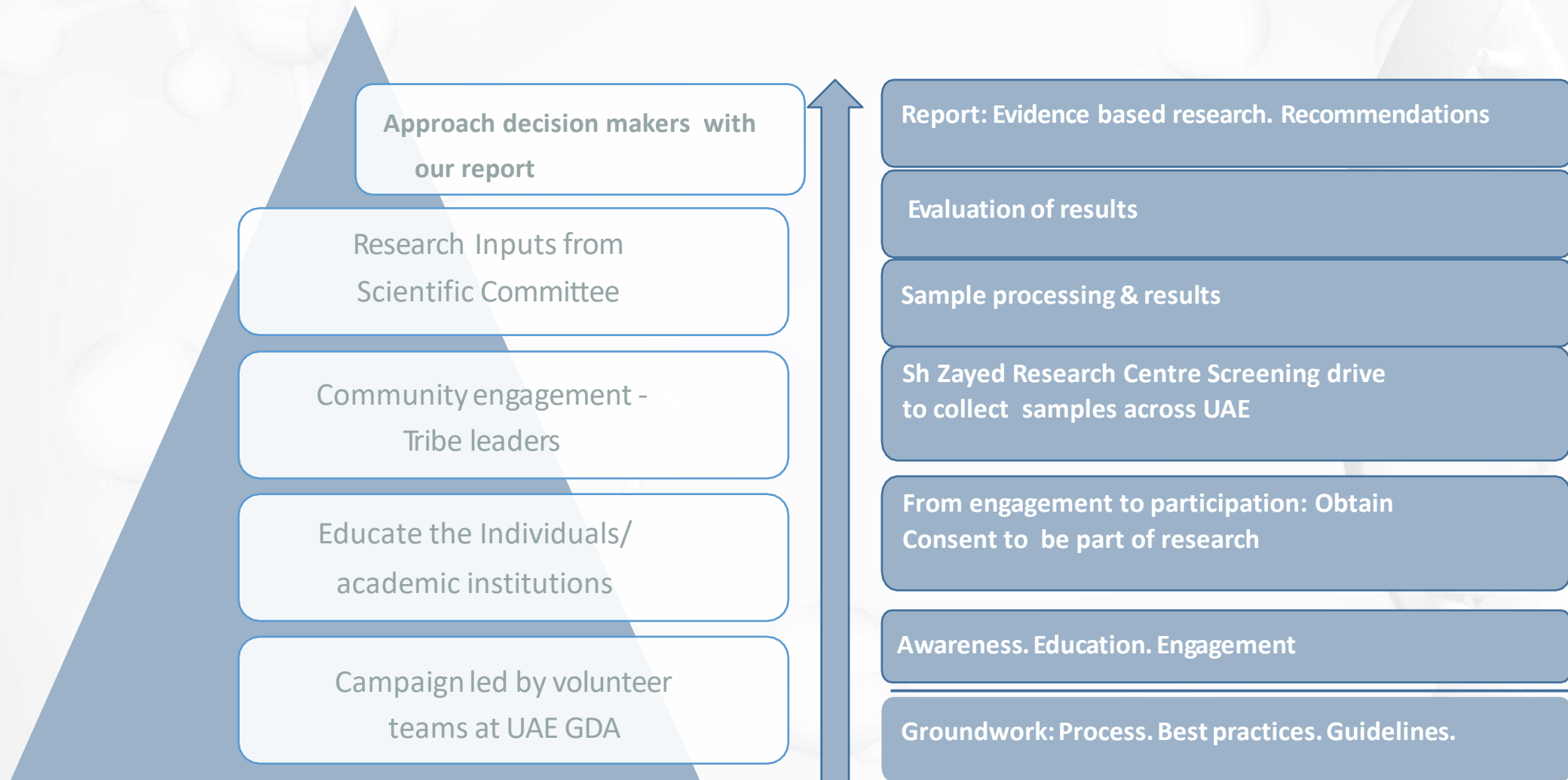
**Empower community to have the credible and easy-to-understand information;**

**Education and tools to take the right decisions at the right time**

**More acceptability of population screening**



## UAE GDA's Award Winning Evidence based screening model





## UAE GDA's Evidence based screening model among top five best case studies recommended by The Health Care Transformation Task Force

### Patient Engagement: Four Case Studies That Highlight The Potential For Improved Health Outcomes And Reduced Costs

Ara Darzi, Hanan Al Kuwari, Jeremy Laurance, Mariam Matar, Peter J. Howitt, Sarah Henderson, Susan Edgman-Levitan

*Health Affairs Journal Volume: 33 Issue: 9*

The energy of patients and members of the public worldwide who care about improving health is a huge, but still largely unrecognized and untapped, resource. The aim of patient engagement is to shift the clinical paradigm from determining "what is the matter?" to discovering "what matters to you?" This article presents four case studies from around the world that highlight the proven and potential abilities of increased patient engagement to improve health outcomes and reduce costs, while extending the reach of treatment and diagnostic programs into the community. The cases are an online mental health community in the United Kingdom, a genetic screening program in the United Arab Emirates, a World Health Organization checklist for new mothers, and a hospital-based patient engagement initiative in the United States. Evidence from these and similar endeavors suggests that closer collaboration on the part of patients, families, health care providers, health care systems, and policy makers at multiple levels could help diverse nations provide more effective and population-appropriate health care with fewer resources.

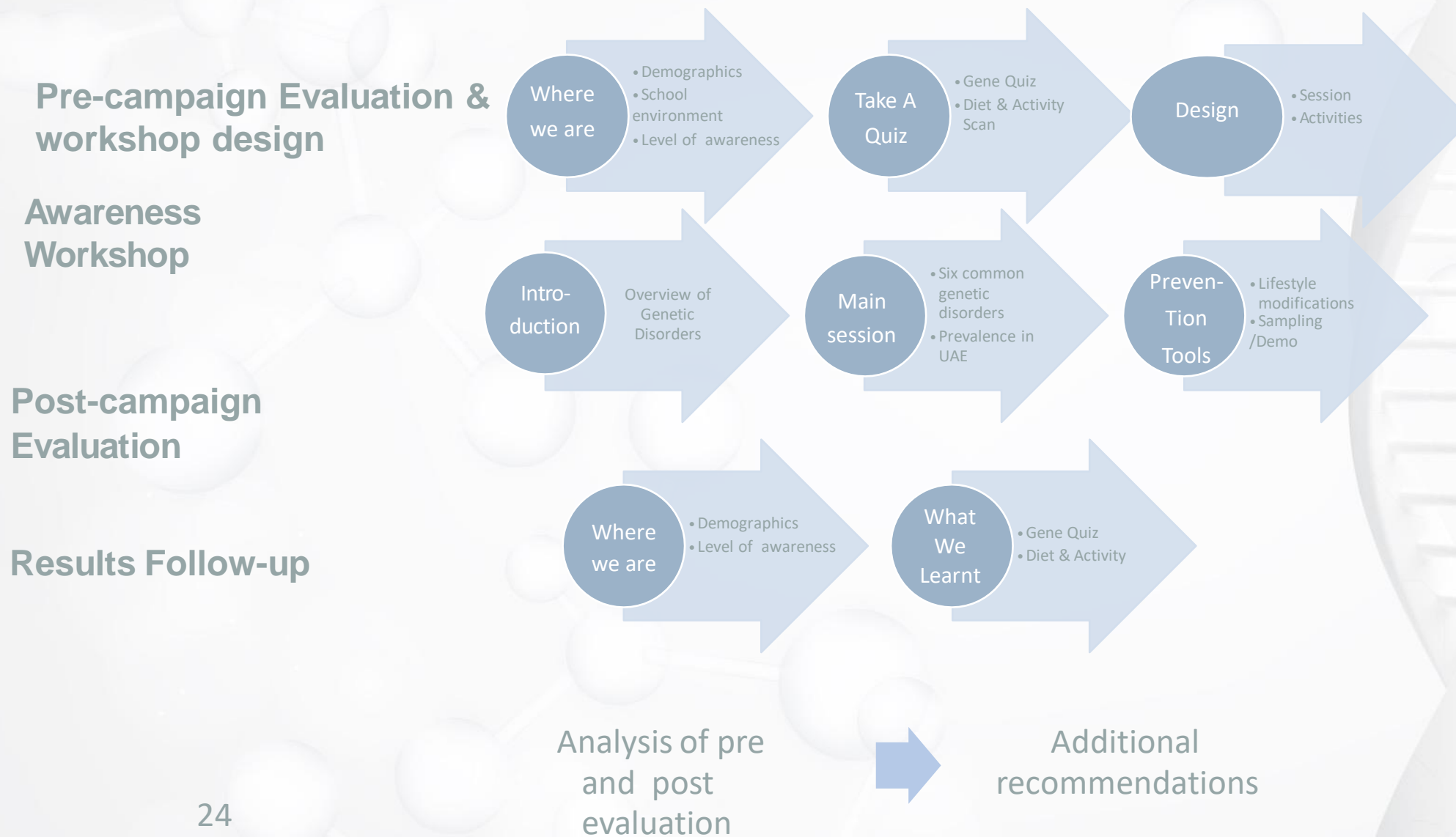


### Developing Care Management Programs to Serve High-Need, High-Cost Populations

INSIGHTS FROM THE  
HEALTH CARE TRANSFORMATION TASK FORCE



# Evidence based Outreach Campaign Process for Schools







## UAE Genetic Diseases Association Sustainable Revenue Generation Strategy 2019 - 2025

The long-term five-year plan looks at opportunities, that are:

- Aligned with our vision and mission.
- Serve the objectives and goals identified in our strategy.

	Project details	Target	Notes
One	<b>Organising regular workshops, seminars and training programs</b> that are held by UAE GDA for training and education purpose e.g. Genetics for non-genetics professionals Awareness programs and events for community	community, medical and non-medical professionals and students	More information is available including the budgets, timelines
Two	Lab training in partnership with Dubai Health Authority and selected international accreditation institutions	Students in final year Medics	More information is available
Three	Strategic partnership and sponsorship of UAE GDA community programs, awareness activities and the student development projects.	Corporates Academic and research institutions	More information is available including the budgets, timelines
Four	International scientific conferences	Global companies, research and innovation institutions and grant and fund agencies	More information is available
Five	Use of the land as commercial projects that are to be developed in sustainable revenue generation through rentals.	Corporates	More information is available

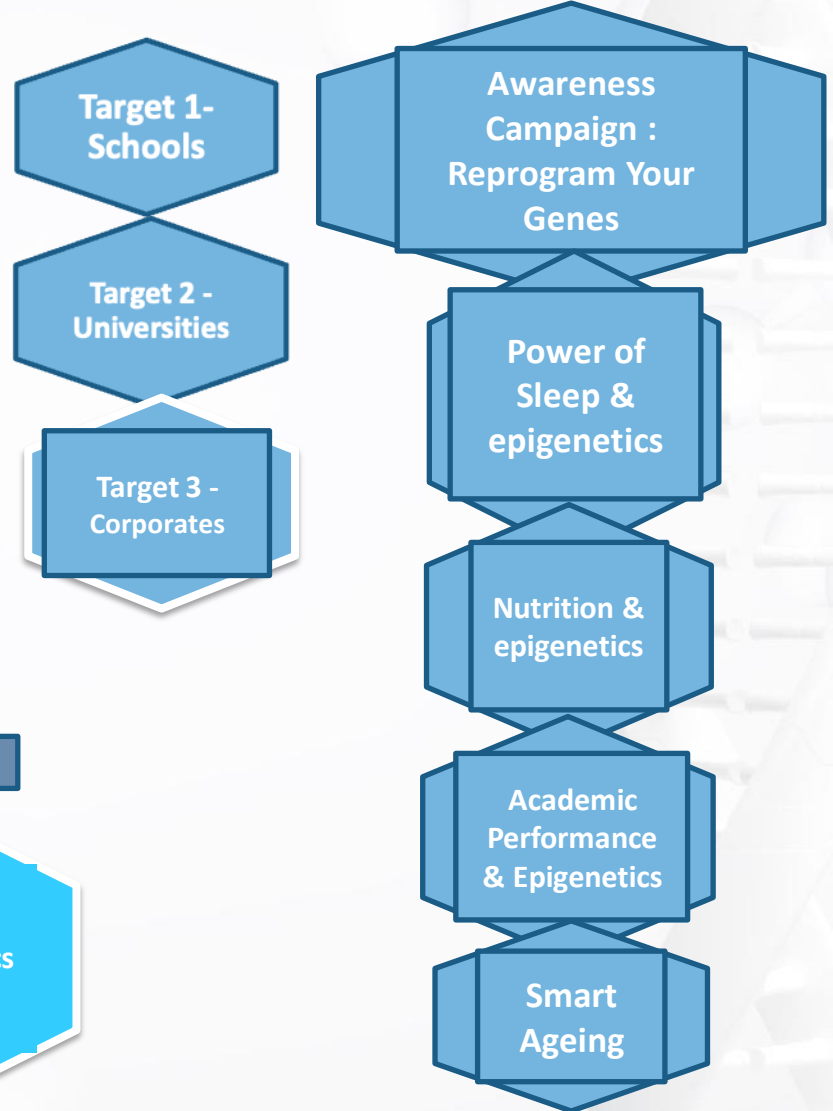


# UAE GDA Projects: Active and in Pipeline

## Scientific Research & Specialists Knowledge



## Community Projects



## Societies Under UAE GDA





## International Knowledge Exchange Platform

The 9th International Genetic Disorders Conference & Awards 2020 (2024)

### Objectives:

- Building UAE As A Hub of Scientific Learning Opportunities in Genetics
- Bring international experts to share case studies, discoveries and research with local researchers, students, medical community – doctors, nurses and staff
- Potential investment in skill building/infrastructure and healthcare support/services by international organisations
- Partnerships and collaboration among research community
- Showcase UAE on forefront of genetic and scientific innovation

### Themes:

1. Epigenetics
2. FEMTECH





## NEW Offer pre-qualifying training for lab technicians

Project in discussion for UAE GDA to become a DHA license pre-qualifying training centre

هيئة الصحة بدبي  
DUBAI HEALTH AUTHORITY

This is first of its kind , structured training program designed because there is a huge gap and need. This training will allow graduate student to get the pre-request experience to apply for DHA license to work as lab technician

- Without the pre request experience student can not start their professional career as a lab technician and hence most of the qualified students DO NOT apply their education and change careers and labs do not get qualified staff.
- The training program is in alignment with and support the UAE healthcare vision 2021.

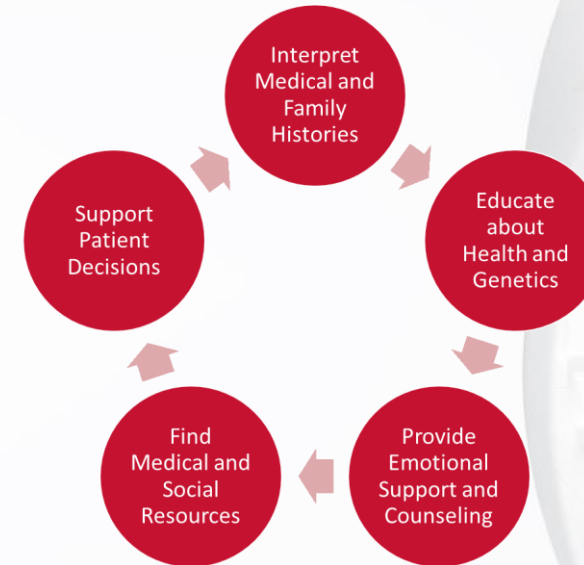
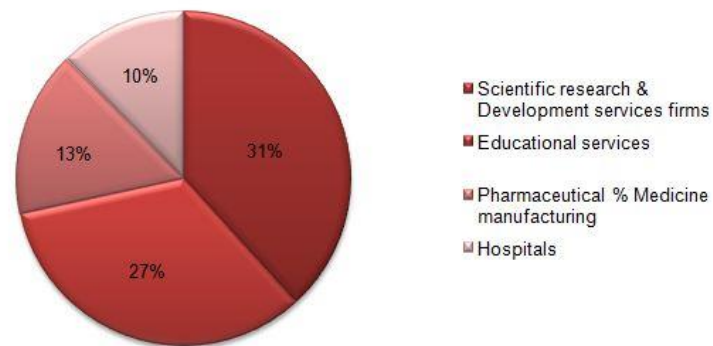


## NEW Genetic Counselling Programs in UAE

UAE and the Arab world has a critical shortage of professionally qualified genetic counselors because:

- No accredited local programs
- Expensive international programs
- UAE GDA will create programs with part UAE – PART global training and masterclasses in UAE

Industries of Employment for Geneticists



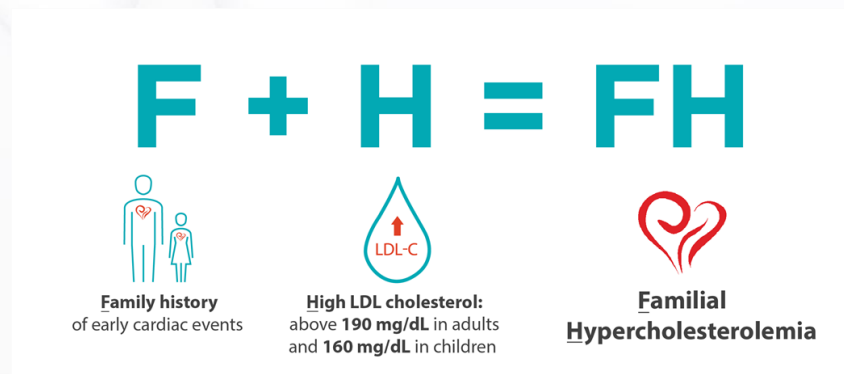
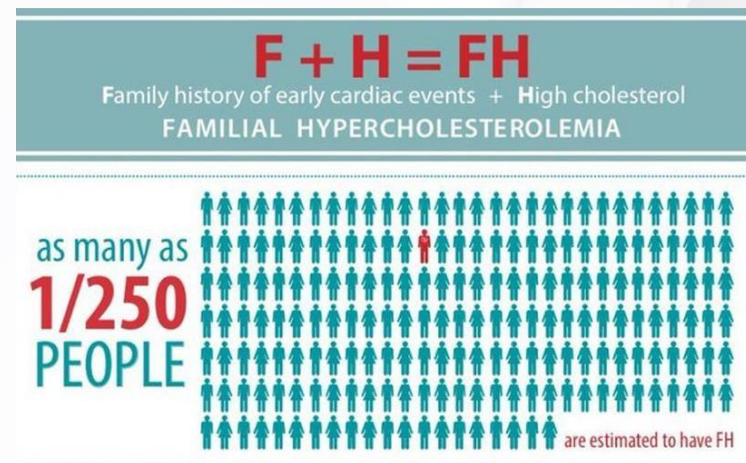
Role of genetic counselors



## FAMILIAL HYPERCHOLESTEREMIA CAMPAIGN IN UAE

A community campaign and research project on the Familial Hypercholesterolemia prevalence, causes, prevention and mutations specific to Emirati population is launched in 2017.

The research will aim to develop diagnostic biomarkers for the early detection and screening for FH carriers among Emirati population





## FAMILIAL HYPERCHOLESTEREMIA

- Familial hypercholesterolemia (FH) is disorder of cholesterol processing that causes very high levels of LDL cholesterol, often called ‘bad cholesterol.’
- These high cholesterol levels lead to plaque build up in the coronary arteries which dramatically increases the risk of coronary heart disease at an early age.
- Individuals with FH may also have cholesterol deposits around the cornea of the eye, in the skin around the eyes and between the fingers, or along tendons.

### Types of cholesterol

#### HDL

**GOOD CHOLESTEROL!**  
High Density Lipoprotein

Good cholesterol (High Density Lipoprotein), carries excess cholesterol in your blood back to your liver where it's broken down and removed from your body. This means a high level of good HDL cholesterol can maintain your heart health.



#### LDL

**BAD CHOLESTEROL!**  
Low Density Lipoprotein

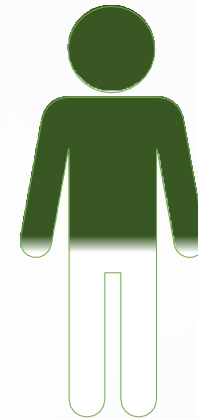
Bad cholesterol (Low Density Lipoprotein) carries cholesterol to your cells. But when you have too much LDL it can build up in your artery walls, causing them to narrow. This reduces blood flow, which can be bad for your heart health.



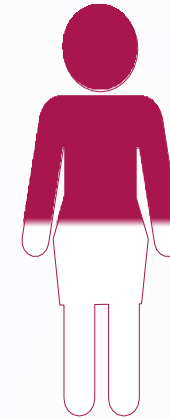


## FAMILIAL HYPERCHOLESTEREMIA PREVALENCE

- The prevalence of hypercholesterolemia (HC) ranged from 17% to 54.9% in males and from 9% to 53.2% in females in the Arab population. Overall, dyslipidemia levels were higher in males than females and increased with age gradually up to the age group of 50–59 when it became stable in some studies and slightly declined in others.
- The average rate of cousin marriages across UAE varies between 40 and 60 per cent.



54.9%



53.2%





## FH HEALTHY BREAKFAST CAMPAIGN IN SCHOOLS IN UAE



### Target audience:

- School students in the age group 7 to 17 years
- Teachers, admin staff and cafeteria teams
- Parents & caregivers

### PRIMARY AUDIENCE Children

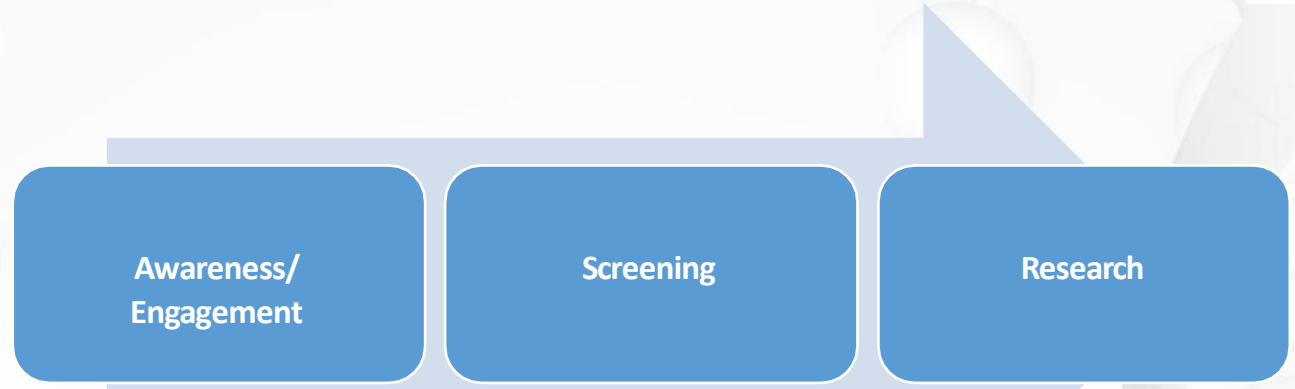
- Engagement Activities:
- Information sessions
- Sampling sessions by healthier Oats of Quaker
- Activities
- Create your breakfast
- Healthier choices
- Pick a better item of the menu

### SECONDARY AUDIENCE

School staff, caregivers and parents

- Engagement Activities
- Epigenetics in Schools
- School Awareness/ Information counters in PTA meetings
- Nutrition demo
- Activities
  - Plan your healthy shopping
  - Read labels
  - Cooking healthier. Eating smarter

Three tier process for research project on FH  
Target population: Emirati students in the age group 18 to 27 year, male and female

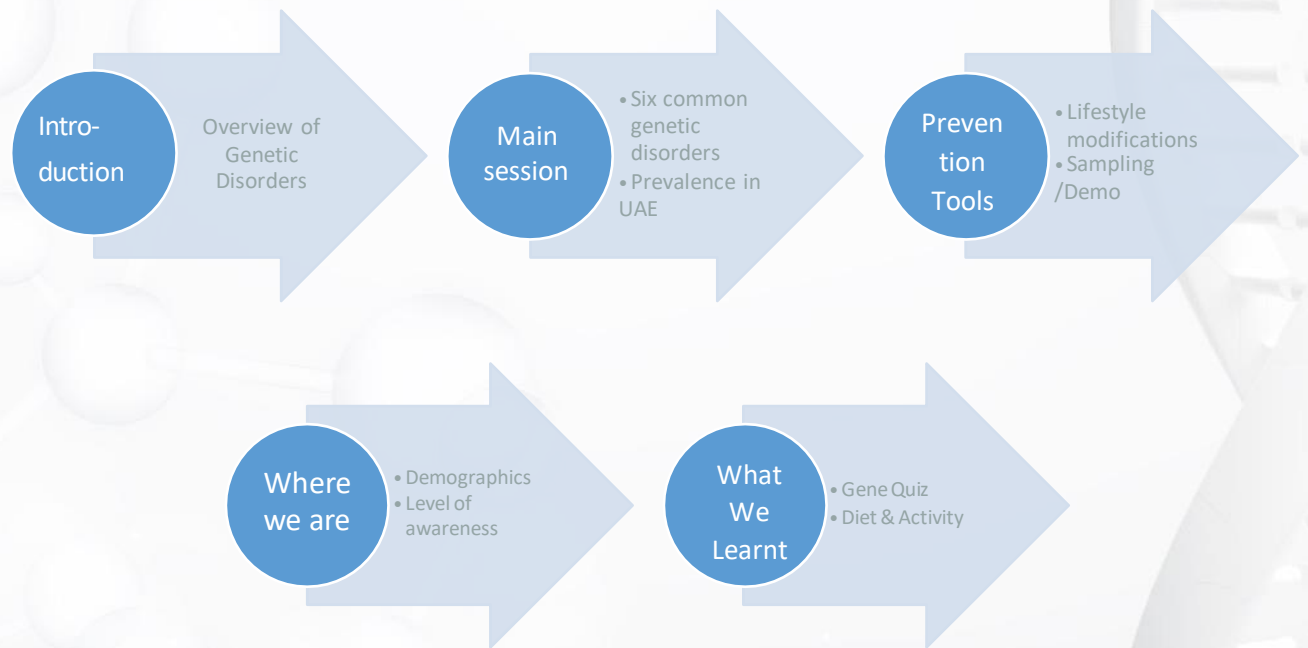


**2017-2020  
Awareness & Engagement**

- Ongoing
- since July 2017
- Continued in 2018-19

**Screening**

**Post-campaign  
Evaluation/Research**





## University Outreach campaign – Focus on FH / All disorders

Campaign	Target	Format
<p>National level campaign for Universities /colleges :</p> <ul style="list-style-type: none"><li>• Awareness day activities</li><li>• Open days/career orientation days</li><li>• Participate in college events related to health</li></ul>	<p>Approx 15,000 Students in the age group 18-24 years in first year</p>	<ul style="list-style-type: none"><li>• Interactive sessions on genetic disorders including:</li><li>• Rare Diseases:</li><li>• Autism, Alzheimer, Celiac Diseases/gluten intolerance</li><li>• Lifestyle educator/Nutritionist on board</li></ul>
<p>Awareness Workshops by UAE GDA</p> <ul style="list-style-type: none"><li>• Most common genetic disorders and special focus on Familial Hypercholesteremia</li><li>• Epigenetics</li></ul>	<ul style="list-style-type: none"><li>• Students</li><li>• Teaching assistant and staff</li><li>• Faculty</li></ul>	<ul style="list-style-type: none"><li>• ‘Take control of your genes’ workshop</li><li>• Role of epigenetics in managing risk factors</li><li>• Awareness of genetic disorders and prevention tools</li><li>• UAE GDA role in screening campaigns</li></ul>



## UAE Rare Diseases Support Group under UAE GDA

### VISION

- To create an active community of stakeholders in Rare Disease within United Arab Emirates, including patients, families, health care providers, researchers & supporters and work together.
- Strive to reduce the prevalence and impact of rare diseases genetic disorders in the UAE.

### MISSION

- Collaborate with rare disease patients, caregivers and other health care advocates
- Raise important awareness for rare diseases
- Offer recognition and support to patients and their families , promote awareness of the specific challenges and needs of those living with rare diseases.
- Create evidence-based studies and offer data support to health care which help in better diagnosis.

### Target Audience

- Our Target audience will be public, medical experts, specialists, pediatricians, health and community media, our partners and families and individuals affected by all rare diseases





## Campaign for UAE Rare Diseases Support Group

Campaign	Target	Activities and Format
Rare Diseases to be a theme for all events	Specialists, media and community	<ul style="list-style-type: none"> <li>Specialists keynote and sessions on challenges of rare diseases</li> </ul>
Rare Diseases Day Of 28 February		<ul style="list-style-type: none"> <li>Specialist event</li> <li>Community event</li> </ul>
<ul style="list-style-type: none"> <li>A public event with activities/sessions</li> </ul>	Communities in Abu Dhabi , Al Ain and northern emirates	
Specialist Engagement Program – increase awareness of rare diseases	Target audience: Physicians , nurses, and hospitals  Information / facilitate doctors to understand challenges/diagnostic/treatment in rare diseases:	<ul style="list-style-type: none"> <li>Participation in conferenced across UAE where UAE GDA Chairperson delivers a keynote/session</li> <li>Two round tables in a year</li> <li>One focused con-current forum during the 2018 conference</li> </ul>
Community programs	For Public <ul style="list-style-type: none"> <li>Autism</li> <li>Alzheimer's</li> <li>Celiac Diseases/gluten sensitivity</li> <li>Irlene</li> <li>Turnery Syndrome</li> </ul>	<ul style="list-style-type: none"> <li>Public Education Forum</li> <li>Inclusion in KHDA campaign</li> <li>Four community activities in the year</li> <li>Inclusion in University campaigns</li> </ul>
Offer support to creation/sustaining patient support groups	<ul style="list-style-type: none"> <li>Offer opportunities to interact and share stories to educate healthcare community and public</li> <li>Guide and assist support groups</li> </ul>	



## Ebtesam: Cancer Support Group under UAE GDA

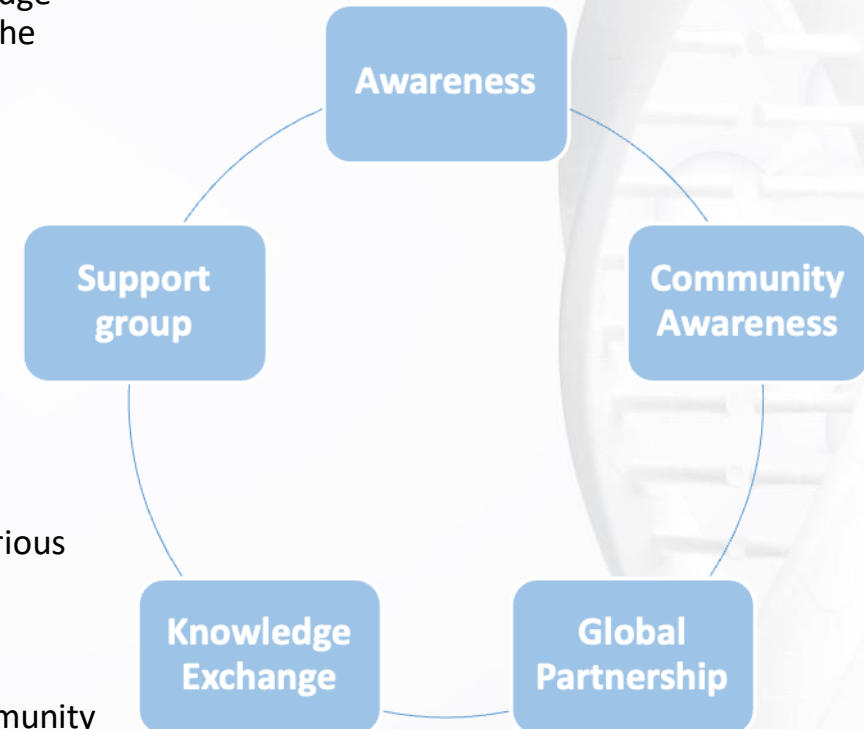
### MISSION

Strive to reduce the prevalence and impact of breast cancer prevalence in the UAE through preventative awareness programs, screening based on research studies and knowledge sharing, conducted by experts in the field using the most innovative technology at the lowest costs.

### Objectives

- Promote awareness and understanding of all type of cancer
- Offer Credible information on emerging sciences of prevention , management and health services with a focus on Cancer and Epigenetics
- Build communication and relationship with relevant specialists to promote a good basis for education and management of Turner Syndrome
- Discuss management, social and emotional development, caregiving through various platforms

**Target Audience:** Public, medical experts, specialists, pediatricians, health and community media, our partners and families and individuals affected by cancer





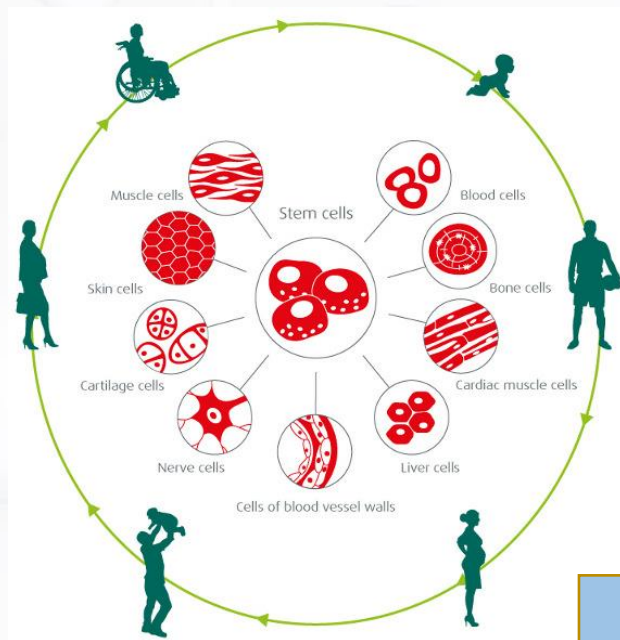
## NEW - Sickle Cell Society/Project

- SC is a genetic disease most common among people from Middle East.
- Gene Frequency and common disease pattern of sickle cell hemoglobin (HbS) in the Middle Eastern Arab Countries as depicted in table 1.
- Among the UAE nationals abnormal HbS is one of the most common disorders and is reported benign to severe.
- Miller CJ, a faculty of United Arab Emirates University conducted a hematological survey of preschool children and reported the frequency of HbS as 4.6 per cent.





# NEW - Cord Stem Cell Storage Project



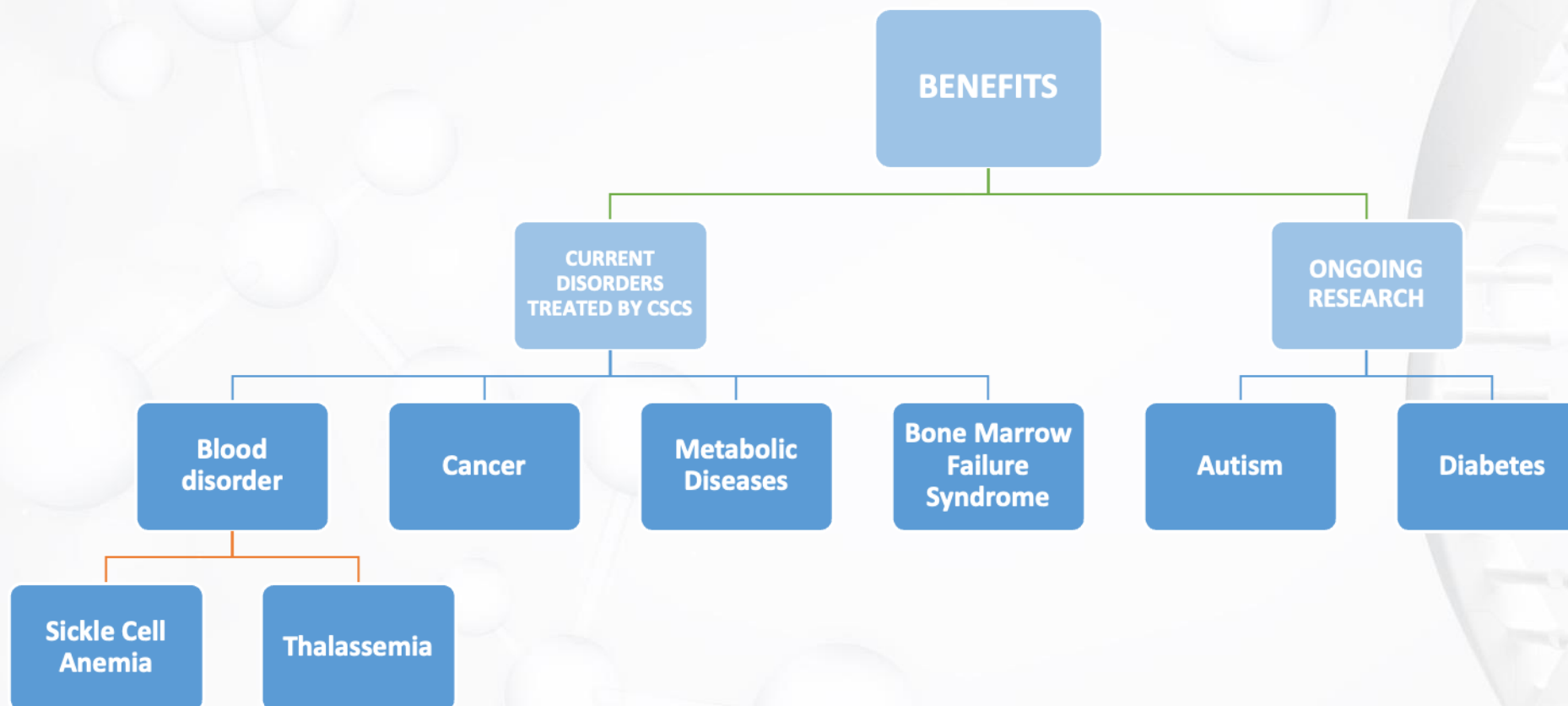
Stem cells morphing into all different types of cells

- Can Cure nearly 70 diseases
- Younger and superior quality
- Autologous matching guaranteed
- Natural and Controversy Free
- Siblings could benefit too
- Readily available after storage





## Benefits of Cord Stem Cell Storage Project





## NEW – Women in STEM

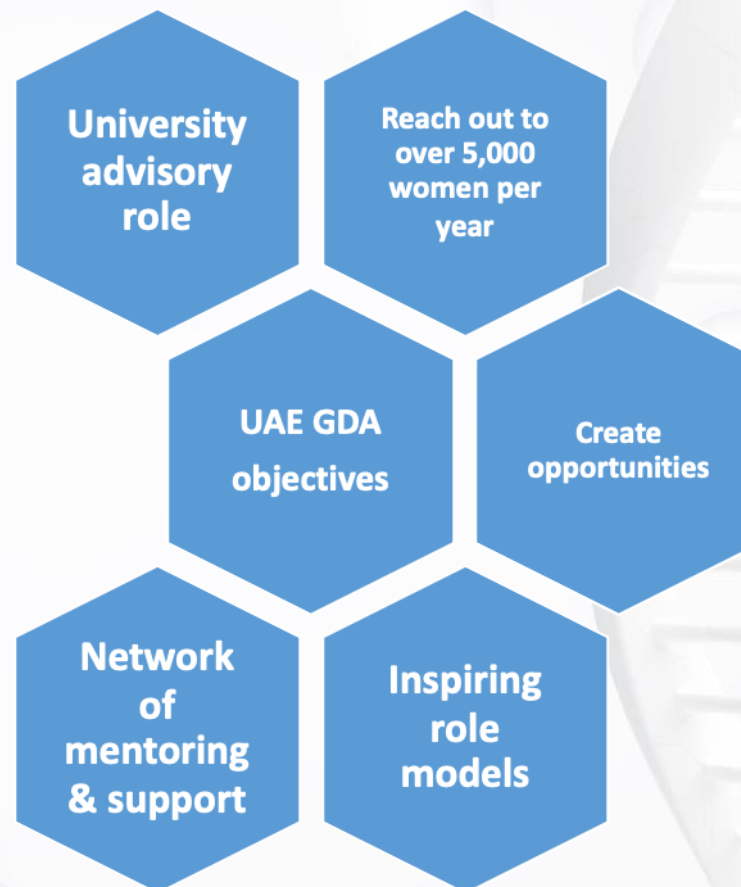
### Women Benefit the Bottom Line

Gender diversity yields:

- » Better, faster problem-solving
- » More experimental, more efficient teams
- » Higher return on investment



Sources: *Workplace Diversity Pays*, American Sociological Review (2009), *Capitalizing on Thought Diversity*, Research-Technology Management (2009), *The Difference*, Scott Page (2007), *Innovative Potential*, London Business School (2007), *The Bottom Line*, Catalyst (2004)





## “UAE Free of Thalassemia 2012” launched in 2004

“UAE Free of Thalassemia 2012” was launched in 2004 to step up the fight against Thalassemia, in line with the UAE federal government’s vision to make the country free from the new births of children with Thalassemia major by the year 2012.

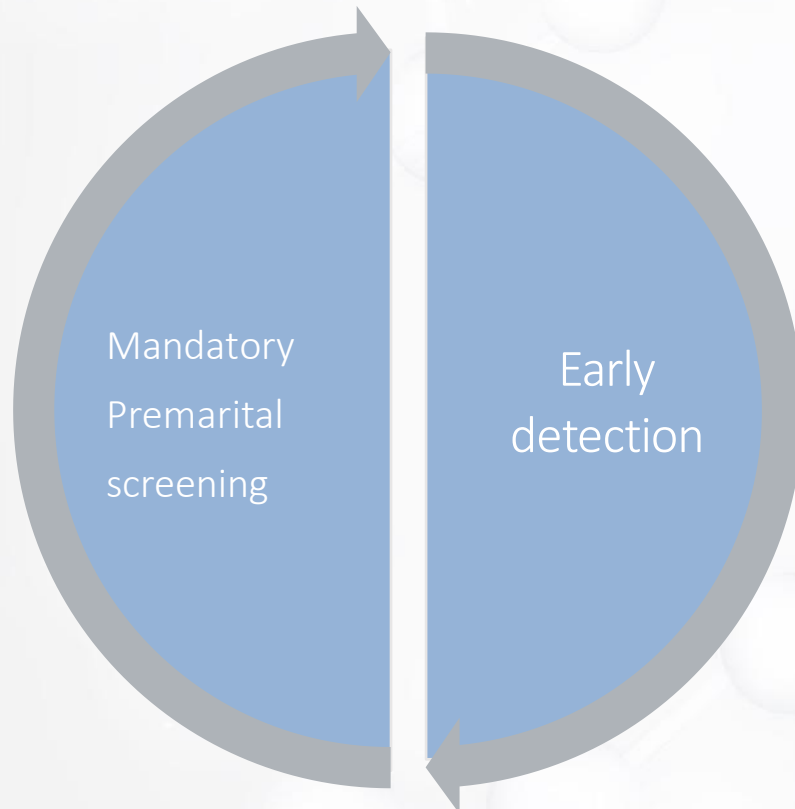
The awareness campaign toward thalassemia prevention is based on the two hypotheses:

- Premarital screening will prevent the intermarriage in the carrier population;
- In addition to premarital screening, if young adults are educated about thalassemia, marriage among the carrier populations will be prevented.





## Thalassemia Management : Screening, Detection and Prevention



With early detection and treatment, most people with haemophilia can have good quality of life.

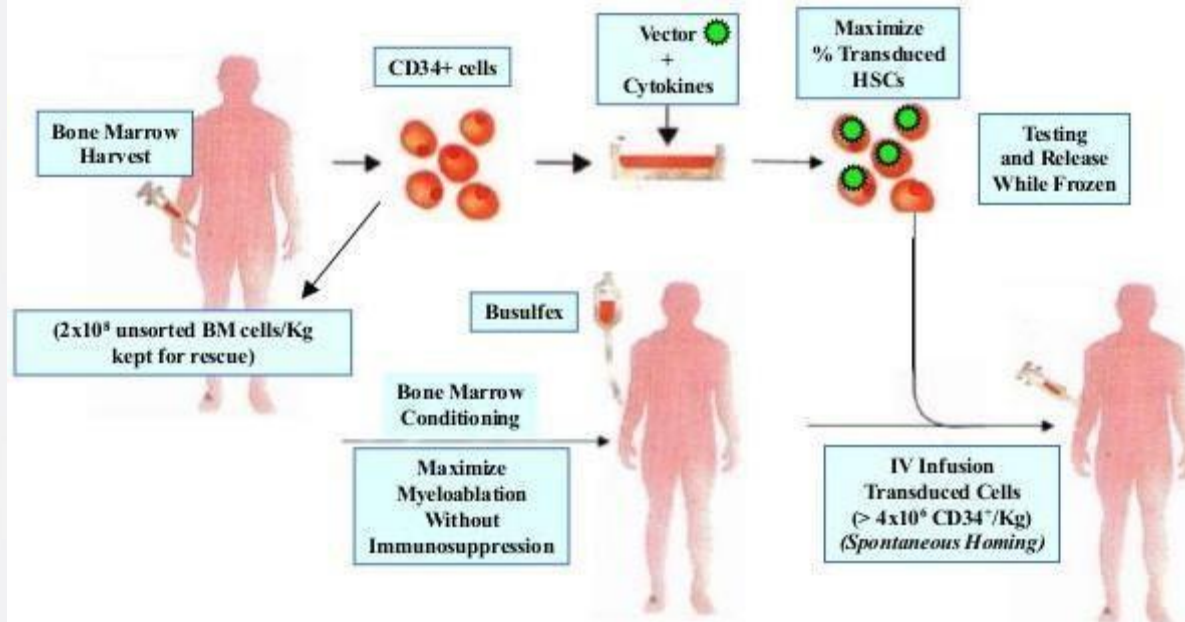
With recent advancement in genetic sciences, physicians can now offer Tailored prophylactic treatment which work best according to the patient's lifestyle.

Such tailored treatment also ensures better chances of the patient living a normal life.



## Thalassemia Management : STEM Cells

### Overview of the clinical protocol



Worldwide scientists are working on the potential of stem cell therapy for blood disorders.

Allogeneic hematopoietic stem cell transplantation has been well established as gene replacement therapy for patients with thalassemia major, and now offers very high rates of cure for patients who have access to this therapy.



## Thalassemia : Recent advances in gene therapy

As thalassemia is genetically derived disorder, genetic and cellular targets are potential approaches in management of disease.

### **Gene transfer using onco-retroviral vectors:**

Gene addition mediated by retroviral vectors is an attractive approach for monogenic disorder.

### **Gene transfer using lentiviral vectors**

**Gene correction and induced pluripotent stem (ips) cells** Reprogramming of adult cells to stem cells and their genetic correction may offer an alternative source of autologous hematopoietic stem cells for transplantation.

### **Splice-switching and stop codon readthrough**

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3425167/>



<b>UAE GDA Field survey conducted form</b>		<b>2007-2016</b>								
	<b>2007</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>
<b>Abu Dhabi</b>	3	460	1785	2233	2315	0	0	8	23	0
<b>Dubai</b>	186	1605	3164	4071	4145	702	200	501	96	27
<b>Sharjah</b>	40	359	538	1007	1135	0	21	32	21	61
<b>Ajman</b>	20	105	162	537	841	605	402	36	0	2
<b>Fujairah</b>	0	75	621	1937	2050	200	0	0	0	
<b>Um Al Quwain</b>	3	46	52	53	53	0	152	0	0	0
<b>RAK</b>	0	303	589	706	742	720	0	0	0	0
<b>Total</b>	<b>252</b>	<b>2952</b>	<b>6911</b>	<b>10544</b>	<b>11281</b>	<b>2227</b>	<b>775</b>	<b>569</b>	<b>140</b>	<b>90</b>



## Impact of Premarital Screening UAE

### Hemoglobinopathies screening statistics 2007- 2017

Total no. of Cases Screened: **32,849**

No. of cases screened positive for Haemoglobinopathies : **16220**

No. of cases screened negative for Haemoglobinopathies : **16629**

TOTAL	B-THAL TRAIT	SICKLE CELL TRAIT	G6PDH	ALPHA THAL TRAIT
16220	1070	482	475	14193
%	3.4%	1.46%	1.44%	42.99%





## Impact of Premarital Screening 2007-2017

### Financial savings to the national healthcare budget

The total cost of medical care per year *	The cost of medical care per case per year *	The cost of each test	All (Total)	BTT (Beta Thal.)	SC (Sickle Cell)	G6PD
32,372,550	35,850	414	14,907	480	203	220

The cost of screening in the government sector is AED 1000 in the private sector is more than AED 1,800

Thalassemia cases only according to estimates by the Dubai Health Authority in 2007: Savings per case for = AED 35,850

Savings for all cases = AED 32,372,550



جمعية الإمارات للأمراض الجينية  
UAE GENETIC DISEASES ASSOCIATION

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# UAE GDA Scientific Conferences and Community Campaigns 2022 - 2023



# Expo 2020 Egyptian genome reference project

Under the title “The Reference Genome of the Egyptians and the Ancient Egyptians”

EGYPT GENOME  
EGYPTIAN GENOME PROJECT

الجينوم المرجعي للمصريين وقدماء المصريين

تحت رعاية

معالي  
الأستاذ الدكتور / خالد عبد الغفار  
وزير التعليم العالي والبحث العلمي  
و القائم بأعمال وزير الصحة  
جمهورية مصر العربية

معالي  
الشيخ / نهيان بن مبارك آل نهيان  
عضو مجلس الوزراء وزير التسامح والتعايش  
رئيس جمعية الإمارات للأمراض الجينية  
الإمارات العربية المتحدة

إكسبو دبي  
31 يناير 2022  
DP World Pavilion الساعة 10:30 ص. بتوقيت دبي

بنك المعرفة المصري  
Egyptian Knowledge Bank

The event was attended by the UAE Minister of Tolerance and Coexistence and the Chairman of the UAE Genetic Diseases Association, Sheikh Nahyan bin Mubarak Al Nahyan, well-known Egyptian cardiologist Magdy Yacoub, Assistant Minister of Tourism and Antiquities for Archaeological Affairs at the Grand Egyptian Museum al-Tayeb Abbas: and a large number of prominent scientists and specialists from Egypt and the UAE.

EGYPT GENOME  
EGYPTIAN GENOME PROJECT

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Egyptian Knowledge Bank

السير مجدي يعقوب  
جراح القلب العالمي

الدكتورة مريم مطر  
مؤسس ورئيسة جمعية الإمارات للأمراض الجينية

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## Expo 2020 Rare Diseases Day 2022 celebration With UAE Genetic Diseases Association



Rare Disease Day takes place on the last day of February each year. This is a global initiative to raise awareness and generate change around rare diseases and their impact on patients' and families' lives. The UAE Rare Disease Society is proud to be partnering with Expo 2020 Dubai to help bring more attention to Rare Diseases by organising this memorable event.

This special day kicks off with a speech from H.E. Sheikh Nahayan Bin Mubarak Al Nahayan, Minister of Tolerance and Commissioner General of Expo 2020 Dubai, and President of UAE Genetic Diseases Association





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## World Parkinson Day April 11 2022

تحت رعاية معالي  
الشيخ نهيان بن مبارك آل نهيان  
عضو مجلس الوزراء وزير التسامح والتعايش  
ورئيس جمعية الإمارات للأمراض الجينية

يتشرف أصدقاء باركنسون الإمارات في جمعية الإمارات للأمراض الجينية بالتعاون مع مجلس أصحاب الهمم بشرطة دبي بدعوتكم لحضور فعالية  
**اليوم العالمي لباركنسون**  
11 أبريل 2022 9 مساءً بتوقيت الإمارات

انقر هنا أو  
دخول الإجتماع

قم بالمسح

H.E. Sheikh Nahayan Bin Mubarak Al Nahayan, Minister of Tolerance and President of UAE Genetic Diseases Association attended UAE Genetic Diseases Association celebrations with People of Determination Council at Dubai Police and Friends of Parkinson UAE. Her Excellency Dr. Maryam Matar, Founder and Chairman led an an interactive session with a wide range of experts.



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## Zayed Humanitarian Work Day April 20 2022

الامارات THE EMIRATES | مجالس آباء دبي | رئاسة بلدية دبي | رئاسة بلدية دبي | رئاسة بلدية دبي

الشيخ الدكتور  
سالم بن ركاض العامري

الشيخ المهندس  
سالم بن سلطان القاسمي

جلسة حوارية بمناسبة يوم زايد للعمل الانساني بعنوان

**زايدك الانبيك**

ضيوف الجلسة :

د. مريم مطر  
الاعلامية دينا مومند

الدكتورة مريم مطر  
مؤسس ورئيس مجلس إدارة جمعية الإمارات للأمراض الجينية

سعادة المحفدة عزة بنت سليمان  
عضو سابق في المجلس الوطني الاتحادي

سعادة سالم النوار الشحي  
عضو سابق في المجلس الوطني الاتحادي

شركاء النجاح:

مركز قوة التطوعي  
مركز قوة التطوعي

المزيد من المعلومات يرجى التواصل مع:

سيف الرحمن 0556088865 | شهاب الحوسني 0503132327

The UAE celebrates Zayed Humanitarian Work Day, coinciding with the anniversary of the death of the Founding Leader, the late Sheikh Zayed bin Sultan Al Nahyan.<sup>1</sup>

Her Excellency Dr. Maryam Matar, Founder and Chairman joined a panel of experts.

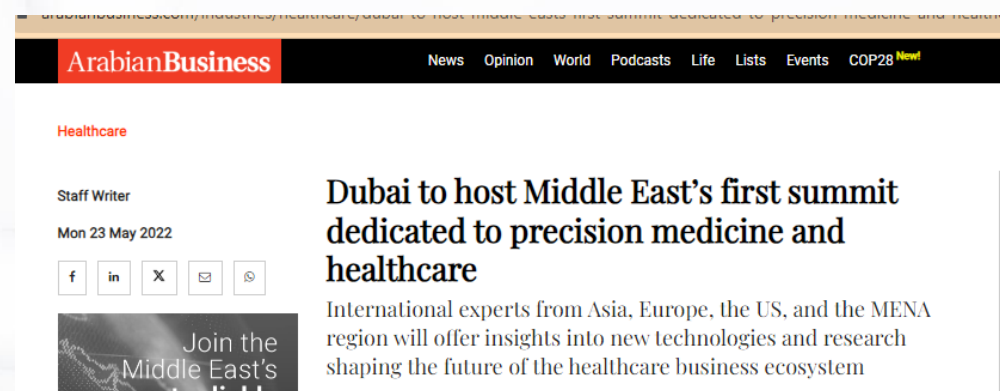


## Precision Med Exhibition & Summit, Dubai, UAE, May 2022



Dubai hosted the Middle East's first dedicated exhibition and summit devoted to the digital technology driven precision medicine (PM) field this month.

The newly-launched Precision Medicine Exhibition & Summit was held under the patronage of Sheikh Nahyan bin Mubarak Al Nahyan, Minister of Tolerance and Coexistence and President of UAE Genetic Diseases Association.







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## The Future Health Summit, Dubai, UAE, February 2023

# FUTURE HEALTH SUMMIT

UAE GDA hosted The Future Health Summit, an exclusive, fully immersive event for senior government officials and CEOs in healthcare. Theme was to explore the future of health and delve deep into the amazing possibilities of healthcare in the Metaverse.

Arab Health

By Informa Markets



Organized concurrently with Arab Health 2023 in partnership with UAE GDA



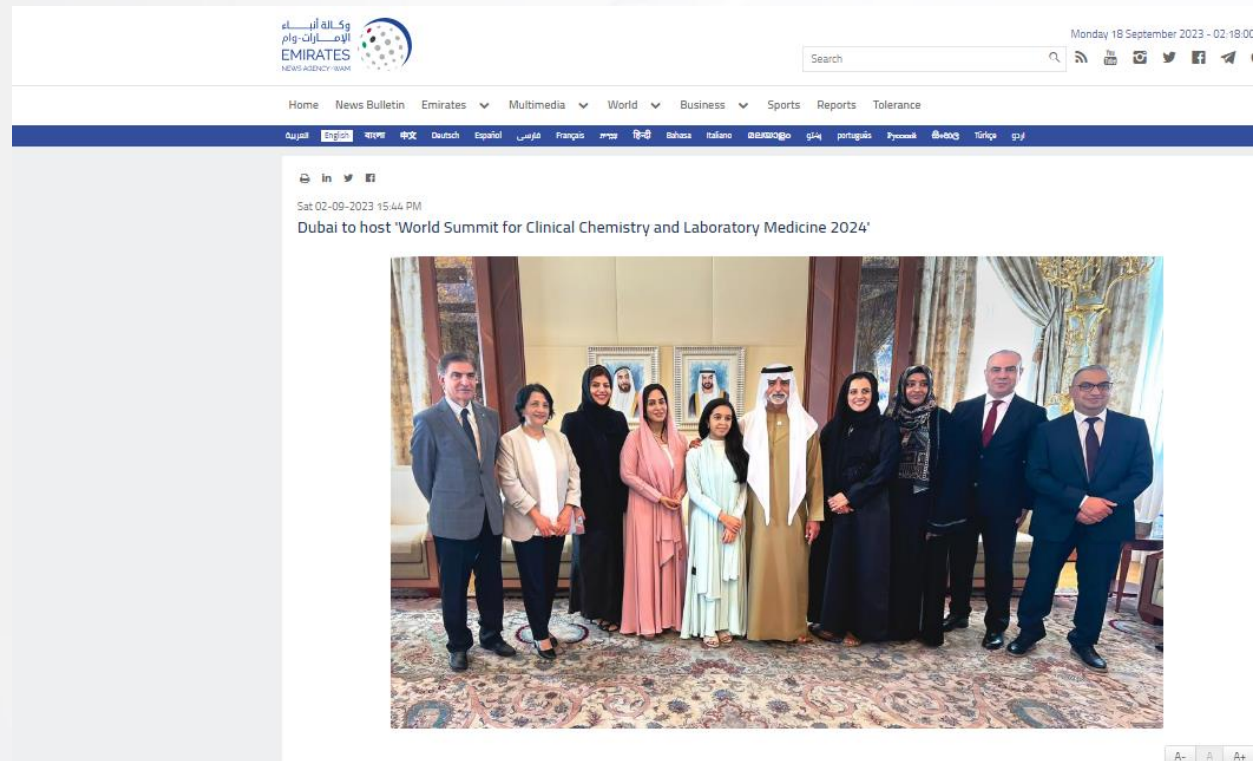
## Genetic Rare Disease Annual Meeting – March 2023



A collaboration between MENA Organization for Rare Diseases and UAE Genetic Diseases Association in Dubai. A unique platform that brought all parties involved in **rare diseases** to one place to obtain the most updated knowledge and increase awareness.



UAEGDA announced partnership with **Saudi Society for Clinical Chemistry and Arab Federation for Clinical Biology** to host World Summit for Clinical Chemistry and Laboratory Medicine 2024



This summit will be held under the patronage of Sheikh Nahyan bin Mubarak Al Nahyan, Minister of Tolerance and Coexistence and the President of the UAE Genetic Diseases Association.

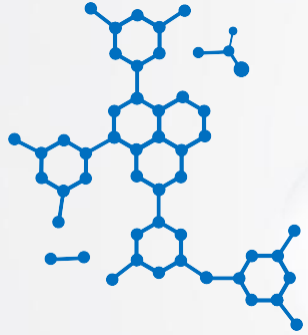


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SHEIKH ZAYED GENETIC RESEARCH CENTRE



# Healthcare Events coming up in Q4 2023 & 2024

## MedHealth Abu Dhabi 2023

24th edition of Arab Hospital Federation Annual Forum  
25 – 26 September 2023 at Conrad Abu Dhabi Hotel – Etihad Towers



The forum will be dedicated to key decision makers, hospital owners, C-level executives, Directors, Clinicians and Healthcare Leaders to get insights on worldwide trends affecting hospitals and healthcare, sharing best practices and solutions while creating a real forum for networking in the Arab countries.



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International Symposium  
**FUTURE MEDICINE  
AND SCIENCES**  
DUBAI - 2023

## International Symposium on Future Medicine and Sciences

ISFMS 2023 - Dubai  
**20-22 SEP**

Organized by



مركز الشيخ زايد للأبحاث الجينية  
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## Suggested Scientific Committee

- **Dr. Ram Kumar Bharadwaj Mantha**  
Assistant Professor  
University of Sharjah
- **Dr. Adil Tamimi**  
Professor  
American University of Sharjah
- **Dr. Karima Hamani**  
Assistant Professor  
Heriot-Watt University Dubai
- **Dr. Hamad AlJassmi**  
Associate Professor  
UAE University
- **Dr. Hatem Abushammala**  
Assistant Professor  
Al-Ain University
- **Dr. Hanifa Al Balushi**  
Assistant Professor  
Khalifa University



Age	
18 - 24	18%
25 - 34	40%
35 - 44	19%
45 - 54	10%
55 - 64	8%
65+	5%

Career Stage	
Early career (PhD)	23%
Experienced (Postdoc)	52%
Senior professional	26%



## Symposium Partners

Endorsed By:



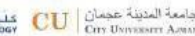
مجمع الشارقة للبحوث  
والتكنولوجيا والابتكار  
Sharjah Research Technology  
and Innovation Park



Indexed in:



Strategic & Academic Partners:



Selected papers will be published in Scopus journals:







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Forbes  
Middle East

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**Healthcare**  
SUMMIT

Innovate, Collaborate, Heal:  
Pioneering the Future of Healthcare

# Healthcare

Summit 2022



**Forbes Middle East Healthcare Summit**

October 8<sup>th</sup>, 9<sup>th</sup> & 10<sup>th</sup> 2023 • The St. Regis Saadiyat Island Resort, Abu Dhabi



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[www.dubai2024.org](http://www.dubai2024.org)



# IFCC WORLD LAB DUBAI 2024

MAY 26-30



26<sup>th</sup> International Congress of  
Clinical Chemistry and Laboratory Medicine

17<sup>th</sup> Congress of Arab Federation  
of Clinical Biology

10<sup>th</sup> Saudi Society for Clinical  
Chemistry Annual Meeting

8<sup>th</sup> International and UAE Genetic  
Disorders Conference

## The 10th NNEDPro Health and Nutrition Summit in Dubai 2024



**NNEDPRO GLOBAL  
INSTITUTE FOR FOOD,  
NUTRITION AND HEALTH**

Social Enterprise | Independent Research Organisation  
Education and Training Centre | Advisory Services



**15  
Years  
OF EXCELLENCE**

From Cambridge to the world  
2008 - 2023

The theme of the **summit** is  
Sustainable Resourcing For All In  
Food & **Nutrition** Security:  
Creative solutions for **healthy** &  
resilient populations





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**Thank You  
for joining Us Today**

**+ 971 4344 4476**

**[www.uaegda.ae](http://www.uaegda.ae) | [info@uaegda.ae](mailto:info@uaegda.ae)**