Maryam Matar – Founder and Chairperson, United Arab Emirates Genetic Diseases Association (UAEGDA)



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25.11.2019

Tags: UAE, Genetics, NGO, Rare Diseases, UAEGDA

The United Arab Emirates Genetic Diseases Association (UAEGDA) was established in 2006 and aims to increase awareness programs in order to prevent the occurrence of common genetic disorders in the UAE and throughout the region. Dr. Maryam Matar is the founder of the UAEGDA, and she discusses the importance of the UAEGDA for the wider community, key priorities for the organization in bringing awareness and education to the community, and how the UAEGDA is tackling the challenges faced every day by people suffering from genetic diseases.

Dr Matar, can you begin by introducing the United Arab Emirates Genetic Diseases Association and explain why there is a need for an organization as such in the UAE?

Our overarching mission at the UAEGDA is public health and prevention. We are a non-governmental organization (NGO) that represents 200 nationalities living in the UAE from Abu Dhabi to Fujairah. Our focus is primarily on the early detection of high-risk groups that develop genetic disorders which may or may not be inheritable. There is a vast difference between inheritable genetic disorders: meaning it is acquired from one or both parents, and non-inheritable: where it is acquired by an individual through external factors. The goal of the UAEGDA is the early detection of high-risk groups who may develop some of the most common genetic disorders in the UAE. Moreover, our purpose is to ensure these individuals are equipped with the knowledge and

education about available, accessible and affordable services that will give them a better quality of life.

What are some of the key priorities of the UAEGDA?

We are a unique organization in the Middle East, as we are the only NGO that has a dedicated research centre, an accredited lab and a clinic that is licensed by the Dubai Health Authority (DHA). Our primary focus is to empower the community with knowledge and information, whilst working toward multiple parallel missions, including academia and research. Firstly, academia is centred around supporting all organizations in the country that are concerned with developing a new curriculum related to all specialties that help us to improve the quality of life for the next generation.

Another part of our work relating to academia is sponsoring the highest achieving students to complete their masters or PhD studies. Furthermore, we ensure that all of the research we implement falls under our umbrella and is fully supervised by a certified university or College. Secondly, we focus on empowering the patients and their families through establishing a patient support group regardless of how it is related directly or indirectly to our projects. Concerning patient advocacy groups, we are looking to ensure patient's voices can be heard and their concerns are fully documented. In summation, our focus is on prevention, early detection and empowering the new generation with the tools that are available and accessible to maintain a better quality of life.

Please describe what activities and initiatives the association arranges to address the needs of patients, doctors, and the industry.

Whatever the health disorder may be, the UAEGDA has decided that if it behaves like a disease then it needs to be altered on the genetic level. Epigenetics is a field of medicine where we address the correlation between our genetic make-up and how external factors switch our genes on and off. It is like a contractor, they build the room, install the ceiling, the electricals, the air conditioning and so on. However, one of the most important tasks is to ensure the button to control all of these features has been installed. The same occurs when we form as human beings; we are made from 46 chromosomes, however, along with these chromosomes there are key switches. For example, one's puberty gene is switched on at a specific time; or when a woman falls pregnant her period is

switched off and so forth.

We have never lived in a time of greater understanding of human genetic makeup and how our genes do not have to determine our destiny. This fact has encouraged the UAEGDA to form an initiative where we collaborate with all specialties. Taking oncology as an example, we are supporting people by providing sponsorships, while at the same time ensuring there is a focus on genetics and genetic predisposition. Moreover, we look to ensure top speakers can come and provide talks on some of the most relevant areas in genetics within the Middle East for physicians and the public alike. I have both an MD and a PhD, yet in medical school I was never taught about genetics or the impact of genetics. Moreover, a person's response to medication depends on our genetic predisposition. For example, if we treat a man of African ethnicity then the best solution is a calcium channel blocker, whereas, a man that is Caucasian by decent will respond better to a Beta-blocker. When I discuss findings such as this with my colleagues from other specialties, they are extremely excited to partner with the UAEGDA because they know we are at the forefront.

We are very proud that either directly or indirectly we have positioned ourselves fairly across the genetic aspects of all disorders, furthermore, in every activity and event in healthcare services. Patient centricity is key to success and we make sure not to neglect our patients at any time. Any activity that we conduct throughout all specialties tends to focus primarily on physicians; therefore, we have changed this by providing passes for the public to get involved. For example, it is mandatory to have a session in Arabic about a topic, it is also mandatory to have at least two bilingual speakers who will take questions and answers from the public. Needless to say, there has been a very large impact and positive response from the community for these types of events.

We have had incredible support both locally and internationally, including five Nobel laureates who came and visited our organization to show their support for us in our mission. When they discovered that we provide all of our tests for free, and furthermore that our clinic is also free, they were very impressed. One Nobel laureate, in particular, wrote in our guest book "UAEGDA is a spot of light in the Arab world for genetic research". He told me that in all his travels he has not seen such a service provided. In Europe for example, if a physician in academia conducts a screening, he will potentially want these results for publication, most likely for a promotion in his career or his work. Moreover, this is either privately funded or covered by insurance, whereas the UAEGDA does not use this information for personal benefit nor publication. The service is free for all nationalities and not only Emiratis which is truly unique and unequalled in most places.

How does having these high-profile individuals help the UAEGDA in its mission to create awareness for genetic diseases both locally and internationally?

The visit from these Nobel Laureates has immensely helped our international reputation. For instance, we hold a conference every two years and invite these Nobel laureates; however, due to their very busy schedules, they often cannot attend. Instead, they forward our invitation to all of their relevant email contacts. This is truly inspiring and is an incredible international network for the UAEGDA to gain exposure and support from. I always make sure to keep close ties across our local and global network which includes specialists in areas such as oncology, podiatry, and anaesthesia to name a few. For these people, we take the time to create an executive summary describing our current projects, as we understand how valuable their time is and they cannot read through everything. The responses from all of these people have been truly inspiring as they remember that everything that we do is free of charge and for people in need. A few years ago, this resulted in a request from the former Minister of Health in the UK, asking for us to be included in a paper for an American public peer-reviewed journal highlighting the UAEGDA as one of the five best practice community engagement organizations for enforcing legislation. In addition to this, we were the only non-profit organization represented.

Finally, what makes the UAEGDA unique is our scientific advisory board which gives complete authority with one exception, which is approving the budget. This creates a strong and collaborative environment where people can tell me honestly whether a particular project or piece of research is worthwhile and so on.

According to the global gene association, there are approximately 7,000 rare diseases and disorders, and more being discovered daily. What are the key challenges faced by rare disease patients in the UAE?

With a greater understanding of gene makeup, gene expression and pharmacogenomics we have realized that ethnicity plays an important role in mutation. There may be different types of mutations that have yet to be discovered. Our challenge in the UAE and something that in the past has made me unpopular with US screening companies is that I do not recommend the majority of screenings available to my patients. The reason being due to a lack of fair representation of my ethnicity in their primary research samples through which they have identified the high-risk mutations related to specific types of cancer. As a result of this, we decided to conduct (in collaboration with another organization) our own research on 49 patients within GCC who all had a

family history of breast cancer, were at high risk of breast cancer, of were breast cancer survivors. When we ran a genome sequencing for these test groups, we identified 21 new mutations related to females in the Middle East that increase the risk of developing breast cancer. As a result, this has greatly impacted the management of cases, the choice of medication, and the diagnosis rate for breast cancer in my own people. Over the past five years, the prognosis rate has risen from 60 to 80 percent.

Another unique aspect of the UAE, and what I believe to be a great advantage over other markets, such as the US, is the UAE will rarely delay a law. They will start with an initial law, however, there is great flexibility in modifying these laws. This flexibility in enforcing laws and modifying them according to the needs of the people is what makes UAE healthcare services extremely attractive. For instance, let's say there is a law restricting a service provider in some fashion, this company can freely discuss the issue with a key decision-maker, and as long there is no conflict it is likely to be modified. Some people see the healthcare system in the UAE as fragmented, however, in my opinion, it is a golden opportunity. We have the Abu Dhabi health authority (HAAD), the DHA and a Minister. This gives us options which in turn provides opportunities.

Do you think the industry should play a larger role in education and prevention in the UAE?

Yes, the government should indirectly involve the education system. For example, an established company in a European country should not merely bring their product to the market, but also their knowledge base as well. Furthermore, they should corporate with the government, NGO's and academia to give back to the community. I strongly believe that the GCC needs to be considered more than just a region but a part of planet earth, rather than companies segregating healthcare into regions such as the Americas, the Mediterranean, Europe and so on. I have been in meeting rooms where companies decide to put more resources and efforts into certain countries due to higher profit margins and I believe this is wrong, the same amount of attention should be given to every region regardless of the population size or demographic. That being said, there has been a considerable leap in recent years between private and public partnerships in the UAE.

The DHA is soon to be implementing the human genome project, as part of the Dubai 10X initiative. How does this help to support UAEGDA's agenda in reducing the prevalence and impact of common genetic disorders and rare diseases in the country?

UAEGDA was established in 2004 and our first screening was completed in 2007. When an organization performs gene mapping, it does not focus on covering an entire population but the higher risk groups within a given population. To identify the high-risk groups, they look at the existing market and previous screenings that have been conducted.

The wonderful part of the UAE is that we work together when focusing on specific disorders. Being an NGO gives us an amazing opportunity to share our data with everyone, and not only the government or private companies, who directly or indirectly serve the national agenda of UAE. Since 2006, we have aligned ourselves under the same mission as the National Agenda of Healthcare, therefore, for each project, we ensure we are contributing to at least one of the missions on the government's greater agenda.

You have been working in various areas and organizations – what are some of the key achievements you are most proud of?

I am most proud of the substantial support of all 17 nationalities who work in the UAE, these people are at the top of their respective fields and helped me to establish the UAEGDA. I am also proud to be the founder of 28 community projects, including 5 that have been approved by the government, which are now official organizations under the umbrella of the government. It is good to see I have helped establish businesses that are needed by the community and supported by the government.

With numerous awards and distinctions under your belt, what would your advice be to the women in the healthcare industry, specifically in the region that wish to be as successful as yourself?

What makes UAE women both unique and successful is the respect we have for not only our culture but also the fact that we value partnerships with our male colleagues. I believe the reason I have been so successful in the UAE, is from the great support of our gentlemen. I am not only talking about the leadership level but also on the personal level, father, husband, and brother.

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