Youmna Ouraybi Ghaziri – Co-Founder, Ana Fareed Health Consultancy

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Following the diagnosis of her daughter with a rare and debilitating condition eight years ago, Youmna

Ouraybi Ghaziri has dedicated herself to advocating on behalf of her and other rare disease patients. Two years ago, she founded Ana Fareed Health Consultancy; a patient advocacy group that gives voice to rare disease patients in the Middle East, where cultural and economic factors mean that few such groups exist. Here, Ouraybi Ghaziri outlines her goals for Ana Fareed – including the establishment of a national patient registry in the UAE – and how she hopes her family's story will inspire positive change throughout the region in terms of attitudes, actions, and policy.

What first brought you into the world of patient advocacy?

Eight years ago, my eldest daughter was diagnosed with a rare disease. Back then, rare diseases were seldom spoken about in the UAE and no society or organisation existed to raise awareness about them. I was based in Dubai and could not find a medical professional who could confirm the diagnosis of my daughter. As a result, I was forced to move to Canada with my daughter and live with my mother in the hope we would be able to see an expert. We were placed on waiting lists for 2 hospitals, one in Canada and the other in the US. After a 6 month wait, during which my daughter

was living with debilitating pain, we managed to finally see a specialist at the Children's Hospital in Boston. She was diagnosed with idiopathic erythromelalgia, commonly known as Man on Fire Syndrome.

It was a shock to me when I was told that this disease has no cure or treatment and my daughter had to live with it for the rest of her life. This is when I began writing my story and interacting with the rest of the world and the medical community. My blog got published on a medical platform where others were able to gain valuable knowledge on the disease and tips on how to manage certain triggers for this condition. After some time, I moved back to Dubai, and my daughter at that time represented the only case of the syndrome in the Middle East.

I decided that my job should be to advocate for rare disease patients and change the status quo in the region. We were not just fighting for my daughter, but for others with visible and invisible diseases, the rights of people with disabilities and other rare diseases and the rights of inclusion in society. Despite my daughter's high academic achievement, she was still rejected from a local school as they could not accommodate her condition, and I was forced to homeschool her for 6 years.

Therefore, to raise a voice I started using social media such as Instagram under the handle name 'TheFireFighterMom' My daughter and I put forward the red hand challenge, a symbol of my daughter's symptoms, and I asked people to paint their hand red and post it on their social media pages.

I was under the impression the challenge would only reach close connections and possibly across Dubai, but to our surprise, it went viral. Until now, it has reached over 20 countries, and it could be more, and really it has given a voice to the voiceless. It was a changing point in my daughter's life as it built her confidence to speak up and she was even invited as a motivational speaker to the school that rejected her previously.

How did you take the next step forward and become a leading voice for patients?

For two years I was undertaking this social media campaign and doing everything I could, including speaking on television, talking on the radio, and doing all the interviews I was invited to do. I was bringing a spotlight to rare diseases in the Middle East and in fact, the red hand challenge became so big that a woman with the same disease as my daughter in the US asked if she could use it to gain a voice and reach Congress, and she did! This was a big milestone for us as this condition is

now getting the attention it deserves on a larger scale.

After this media push, I got involved with the UAE Rare Disease Society and became a member, giving talks and speaking at seminars. I was then selected to organize the UAE Rare Disease Day at EXPO 2020, which was the biggest awareness event ever done on rare diseases in the whole region. We need to grow the voice of rare disease conditions because even the pharmaceutical industry is not aware of the patient journey. Making them more aware will mean they focus more R&D efforts in this area, such as clinical studies.

What we also notice is that in places like Europe and the US, the patient voice is the strongest and their needs drive innovation. In the Middle East, most of the talks and societies are run by the scientific and medical community. Only patients know how a disease truly impacts their lives so they must also speak for change. This is where the idea of a patient-led advocacy group came up, and I named it Ana Fareed which is Arabic for “I’m Unique.”

Why were other families not as vocal as yourself in advocating for the rare disease patient voice?

There are two reasons behind this. Firstly, the stigma and taboo that comes with a diagnosis. My daughter and I had to show people that living with a rare condition is not something to be ashamed of. We want them to not see themselves as rare, but unique. Secondly, many lack the tools to do so, such as the confidence to do public speaking or the education on how to go about it. Many families and patients are immersed in their daily struggles with the condition and do not have the time, so giving them the tools and platform they need is a good first step.

Overall, we must understand that doctors cannot be the only ones speaking up for us as they only see the face of the diseases. The patients and families see the entire patient journey and understand what really is required to live with such a condition.

How receptive is the pharmaceutical industry to the patient voice, a new concept for them in the UAE?

At first, there may have been some hesitancy, but once they understood how our mission’s role is to empower patients, they were very supportive. They are medically in touch with treatments, but they do not know everything a patient needs. For Rare Disease Day 2023, I asked various pharma

companies to join the Ana Fareed Thumb Print Challenge, and many supported it. This shed a more purposeful light on their role j and that the innovation they bring to patients is making a difference and must be their main focus. Our role is to bridge the gap between patients and industry, which will in turn give companies the drive to even bring more rare disease R&D operations to the region.

Success is defined in many ways. What do you define as success in your role?

Success for me is when I can help other ambassadors advocate for patients' rights, and they can do so even better than myself. We need to empower people and patients and give a voice to the rare disease community. I am encouraging everyone to deliver actions on this topic, not just talk about it. In fact, I'm also confident that our stories will inspire even policymakers to adopt new policies that govern more rights for the rare disease community.

What is your goal for the future?

We need a national patient registry for the UAE; governed by all the different stakeholders; the government, pharmaceutical companies, and the medical and patient community. I want to extend more bridges of awareness and advocacy across the GCC to make this a wide register so there is no fragmentation in the regions and all patients are accounted for.

By the end of the year, I hope a round table brings all stakeholders together and delivers concrete actions and results. If a mum like myself can make such a large change, imagine if we all were driven and empowered for a revolution in the fight against rare diseases.

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