

Namibia Alliance for Rare Diseases

Namibia - Southern Africa



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1. About

Namibia Alliance for Rare Diseases was formed in 2020 to bring together all smaller rare disease persons and organisations to function as a Rare Disease Alliance in Namibia. My name is Bianca Özcan I am the Founder of Multiple Sclerosis Namibia, Co-Founder of Namibia Alliance for Rare Diseases (NARD) and serve as a Patient Advocate for both Multiple Sclerosis Namibia and Namibia Alliance for Rare Diseases.

My motto as a Patient Advocate is:

“Where there is hope there is life, and as long as we are alive we need to give back empathy and kindness, no patient have to suffer on his/her own”.

2. Mission

My goal is to raise awareness about Rare Diseases in Namibia and to connect patients, health professionals and the health ministry in Namibia. Often patients are not aware of the right protocols to follow, so being a Patient Advocate allows me to do that necessary consulting work to make the correct link. My goal is to make a positive difference in our health system and to be an advocate for early diagnoses, easier access to medication and a positive fulfilling life for all patients affected with a Rare Disease. My driving force is the memory of my late son as a result of a

Rare Disease. During his illness, he was the most resilient and positive boy alive. He gave my hope when I had none, to continue our battle with a Rare Disease. I'm driven by the memory of my son and the trauma we went through, to make the battle for others less traumatic. It's all for his memory! As a Multiple Sclerosis patient myself, I can relate to everything a patient goes through and so I find healing when I see patients can be supported! My priorities are to provide education and guidance to patients and caregivers to empower them to stand up for themselves and to know how to address certain issues with their doctors, promoting patient equality, speaking on behalf of patients, preserve human dignity and provide resources.

3. Focus.

We held two very successful annual Rare Diseases Seminars, whereby we educated on different Rare Diseases in Namibia. The event was open to Medical Professionals and the Public, we continue to raise online awareness and we had a major breakthrough when a Public Neurofibromatosis Patient was assisted through government funding to have his full operation covered via a Private Hospital (because the Public Service did not had the facility) to the value of €20,480. We are very appreciative of our Ministry of Health who supports Rare Disease Patients in Namibia.

4. Coming up

We continue to look for patient advocates which we can assign per Rare Disease in Namibia, who will fill the role of contact person for that specific Rare Disease. We are planning to take part in the chain of lights event for World Rare Disease Day. Our major challenge is funding, patient register and a centralised country data system that can capture all the different Rare Diseases we have in Namibia. We also need top of the art training to ensure we are in line with the latest research news and medicines available. We had a media briefing late last year to encourage Namibian citizens that suffer from a Rare Disease to make contact with us, and surprisingly we had more than 15 different types of RD's to the fore. This was a shock, yet an eye opener of where the need and prioritize should be focused at.

