

## The weather in Egypt is very hot and dry. In Cairo the temperature can reached to 100:105F

I would like to introduce myself to you. My name is Mohammed Abdel-Rahman Ali, from Cairo Egypt. I feel so fortunate to have been born on a winter day in November. When I was six months old my mother started to suspect all was not well with me. My body was always hot and dry. My mother went to seek the advice of many doctors. Medical opinion given was that I suffered from fever, as my body temperature was constantly hot. Much medication was administered for fever to no avail. My body was constantly hot. My mother noticed more symptoms as it became obvious that I did not perspire with these extremely high 'fevers'. Finally my mother found her way to a hospital which explores genetics. Further testing was carried out on me and all were surprised to find I suffer from ED. This is a rare condition and had not as far as was known been seen in Egypt previously.

This was to be the beginning of my family's journey with ED. Little was known of the condition when I was diagnosed. No medication was offered. The only treatment known was to avoid the sun and keep the patient in a cool climate. My family was advised that all that could be done was to keep me in water to keep my body temperature down.

My grandmother prepared herself to care for me and facilitate a life for me. I consider her my ideal mother, devoting her life to me. She never left me alone as other family members, including my mother, had no option but to do. She was beside me encouraging me to go on when I hated my life and wished for death. My mother could not cope and depended on her mother-in-law to care for me.

When my body was overheating, my grandmother would advise me to fetch a dish full of cold water to place my feet in. Even the touch of cotton bedding was uncomfortable and hot and I was unable to sleep. I would sprinkle water on my bed to cool the linen. When sleep still evaded me because of the heat, my grandmother would carry a fan to me or on occasions carry me to the top of the house at midnight to enable me to cool my hot body, finally enabling me to sleep. I could not wear any clothing in hot weather, as my body would be extremely overheated. At the age of seven my face revealed not a child but a person of seventy. I was isolation and felt unloved, afraid to speak lest I was made fun of. At the age of ten my first denture was made and I hated it. My younger sister would taunt me if we quarreled. She would call me "Y' Mohammed Denture", and I would become angry and hurt, take the denture from my mouth and throw it from the window, smashing it.

My high school years were very difficult for me. Going to school and studying with this condition was a huge challenge. We lived in an overcrowded house in a lower working class area with a low standard of living. It was depressing. Compounding the situation was the extreme high temperature and discomfort that this brought. To overcome the discomfort and try to cool my hot body, I would wet my underclothes before going to school to try to relieve the discomfort.

My self-esteem suffered greatly as people stared at me, made fun of me and called me an old man. I did my best to overcome the cruelty and face the difficulties. Adversity gave me strength to progress in my study and achieve a university placement to follow my dreams. The sense of pride was profound when I achieved my high school certificate.

My mere existence had been a challenge, but to achieve beyond that showed I had triumphed against Ectodermal Dysplasia, it had not defeated me and I was achieving my dreams. This was a huge turning point in my life and as long as I breathe, I will follow my dreams. I have now joined the American University in Cairo. The NFED gave me a chance to find and improve myself. I pray to God to measure up to the love and encouragement I have found in the NFED family. I remember their sentence "You can do anything you set your mind to". I have set my mind to overcome adversity and achieve my dreams with that statement as my banner.