

20 de Dezembro de 2007

Dear Sir or Madam:

On the second week of January I will be trekking the hills and trails of Mount Kilimanjaro, in Tanzania, Africa. This particular mountain in Africa is the largest freestanding mountain in the world, and rises to an incredible 5,895m high. It is best known to the Masai people that live close by, and they call it, "*Oldoinyo Oibor*", meaning The White Mountain.

The main reason behind this trekking journey is to raise awareness and praise those who fight every day against a disease that is hardly known to the majority of people, but sadly affects so many, which includes my sister. This disease has a name and it is commonly called "*Neurofibromatosis*", a small description can be found in the following link, www.apnf.eu (APNF- Portuguese Neurofibromatosis Association, page).

"The Neurofibromatosis or NF is a genetic disease and can occur, in the majority of cases in two forms: NF1 and NF2.

An increasing variety of genetic diseases are known. The NF is relatively common, being the NF1 the most frequent type of the disease, in contrast with the NF2. Current estimations indicate that 1 in 4,000 individuals are born with NF1. NF2 is less common but estimations point to 1 in 20,000 individuals. To have NF, the person in question, has to have been born with the disease, it is not something that can be caught during the normal life path, and it is not a contagious disease. In the mean time, the signs and symptoms can only manifest, at a later stage, and not just at birth."

This was the my sister's case. During many years no major problems were detected, suddenly "out of the blue", she started to hear less. Immediately, medical examinations were made which shown proved she was carrying the defective gene, responsible for the tumors in her hearing canal, and other problems as well. The presence of two tumors indicated the type of NF; in her case she had NF2.

To me, the reminder that still haunts my mind, and drags my heart, is an episode that is described below:

I entered a room of an American Hospital and saw my sister in a bed, with such a fragile look, plugged to her there was an enormous amount of tubes and electronic devices; my mother's face was in tears in panic and washed face of my mother; the panic feeling of incapacity, pure sadness, resignation that fell upon us made me feel weak. This feeling was so intense that I was hardly able to contain the strong emotion that wanted to burst down my eyes, in a liquid form, as a volcano on the brink of explosion. But this was not what I showed! With force and determination, I acted as everything was well and wishing that hope can't still live inside that fragile and small body. This gave me an unimaginable force that I tried to transmit to my sister; during our conversation. I tried to divert her attention to happier thoughts, and make her not to focus her mind on what had just happened: the fact that she had lost her left hearing capacity, that death had touched her for brief moments, and that all her plans had finished. Then I turned back stumbled, and almost fell, then I told something funny, and soon I got what I was searching for, a smile in her face, a light of hope.

It's on that light that hold my hope, the light that needs to be shown to the world, so that all those who go through such occurrences do not fell walk alone, and do not feel as an "ending to the story".

The Objective is to inform about this disease, to better understand it, and at the same time, to collect funds that will revert entirely to the APNF- Portuguese Neurofibromatosis Association. **The costs of this trip will be, fully supported by me.**

- Make a Donation, your contribution is vital -



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All the information about this adventure will be updated in my personal webpage <http://mauriciosantos.bloguessoal.com/> and at www.apnf.eu. In case you have any doubts or information you can contact me through my email: santos_mauricio@hotmail.com

Best Regards,

Maurício Miguel Abreu dos Santos