

ASID / IPOPI REGIONAL PATIENT MEETING

Hope for Africa

Ithemba le Africa Congress 2013

Sun City , SOUTH AFRICA

5-9 June 2013



HAJAR, Association
d'Aide aux Enfants Atteints de DIP



PID in Morocco: Challenges and Opportunities: Perspectives for patients

Introduction

Hajar is parents and patients association created in 2000 after the death of a little girl whose parents means were not sufficient for an allograft

the needs of patients or their parents for each disease is to:

- have an early diagnosis
- Identify medicines or interventions necessary to cure.
- Or in minima, to know how to manage the disease in hopes of developing a cure through research, while trying to live a normal life.

PID in Morocco: Challenges and Opportunities: Perspectives for patients

The role of parents or patients' association is to fill the existing gaps in one or more of these components, or to contribute to their development through:

1. support for families and patients
2. the lobbying with the government and politics to address existing deficits
3. Looking for funds and resources to support the necessary actions to achieve the objectives of quality of life for all (research, training, education, financial support, ..)

After almost 15 years of existence, Hajar has focused its efforts on the axis 1 of the first 10 years and since 2009, it changed its strategy to work on lines 2 and 3.

PID in Morocco: Challenges and Opportunities: Perspectives for patients



Communication about Hajar activities and fund raising

Awareness caravan





Presence in scientific congress



The international networking

PID in Morocco: Challenges

The challenges for the coming 5 years are:

- have a center of excellence for DIP with allograft teams. An agreement was signed for the construction of a center dedicated to the DIP in UHC , with donor funding
- promote local support patients through the establishment of teams of doctors , nurses and specialists in each region of Morocco. two Specialists in transplantation are ready to act, after training in specialized centers
- ensure early diagnosis of DIP through awareness of the various parties (doctors, parents, schools, ..)
- ensure access to care for all (now 55% of medicines are pay by Hajar)
- to know the DIP nationally to achieve diagnose the largest number of cases of DIP
- have average growth with the number of patients
- obtain charitable status in order to draw more funding

PID in Morocco: Opportunities

- First contact with the Minister through the godmother of the association (Actress Samia AKRIOU)
- availability of funding for the center of excellence for DIP and multiplicity of donors and benefactors
- extension of the possibilities of communication (radio, social media, internet, ..)
- creation of a national fund for the financing of transplants and the possibility to incorporate allograft
- implementation of RAMED to support care for needy families
- creation of AMO (Obligatory health insurance) to provide access to care for all active people

PID in Morocco: Perspectives for patients

- access to allografts, with cost 10 times cheaper than in Europe
- access to medicines (IG, ..)
- Early diagnosis and care in good conditions
- a recognized scientific community
- a gradual assumption of the role of the ministry of health in taking in charge the medicines and allografts to allow Hajar to tackle other areas of support to DIP (education, research development, promotion, training, ...)
- a total socio-professional integration of patients (education, access to jobs, ..)
- Prevention through screening