

## Let's protect the Moon Children (« Enfants de la Lune ») of Tunisia

The Rotary Clubs of Ferney-Voltaire, Gex-Divonne and Bellegarde (District 1710) have joined forces to carry out a project to help the Moon Children (« Enfants de la Lune ») of Tunisia. These children suffer from Xeroderma Pigmentosum (XP), a very rare genetic disease triggered by UV radiation and manifested by cancerous tumors of the skin and eyes. The only treatment is to protect the child from the sun; from head to toe by dressing them in a kind of medical suit! Tunisia is the North African country with the highest density of cases.

This action has therefore consisted in designing and producing new generation masks, replacing the previous helmets: these innovative protections are indeed equipped with a fan whose power supply is provided by a rechargeable battery through a small solar panel. The provision of these first masks was made possible by the collaboration between the clubs already mentioned, the French Association of Moon Children, with the contribution of Mrs. Chaabi, its president, the Rotary Club of Tunis El Menzah and the Association for Assistance to Children with XP in Tunisia. The Rotary Clubs of District 1710 provided the various components; the tissues needed to manufacture the hoods, the work of assembling and the first tests, under the authority of Dr. Zghal, dermatologist and specialist in this disease, were taken care of by the Tunisian associations. The first 25 masks supplied were allocated according to the priorities established by Dr. Zghal. In a second phase, and with the financial support of District 1710, the number of masks was increased to 100. The delivery of the components is underway for a finalization of the assembly of the masks towards the end of the year 2020.



*First masks distributed to children in Tunis. This operation was carried out in collaboration with the Tunisian Association for Helping Children with XP.*

After these two phases of project implementation, we wish to launch phase 3, i.e. to cover the needs of the entire country, which to date has about 700 children suffering from this disease. In order to face the cost of phase 3 we are preparing a request for a Global Grant (GG) with our partner the RC of El Menzah of Tunis. The cost of this third phase is 40 000 euros. To date we have promises of participation for half of the amount. To cover the second half we count on your club and your district to support us. Thank you for your support.

*Aspects for sustainability of the project:*

The protection of children must be ensured throughout their lives, first children then adults. It is therefore planned to complete this initial phase of supplying 700 masks with a second phase, which will ensure a follow-up of these children as well as the maintenance of the components.

The hooded helmet has an average lifespan of 3 to 5 years depending on how it is used (the tissu part is replaced every 2 years, the visor every 3 years and the battery every 3 years). It is therefore important to schedule annual supervision visits to ensure the proper functioning of this project.

In addition, the child and his parents must be trained to optimize the life of the mask, to control the battery charge to prevent dry breakdowns and to intervene in the event of minor breakdowns.

To ensure the start of this follow-up, we propose to offer one of the Xeroderma Pigmentosum patients a part-time association. This person would carry out these two training tasks in the premises of the Association "Enfants de la Lune " Tunisia. Indeed, the association has a 150 m<sup>2</sup> room. It already hosts a computer club and a music club (funded by the Ministry of Higher Education) reserved for Moon Children. One person, currently studying at the Institut Supérieur des Cadres de l' Enfance (ISCE) of Carthage Dermech, is being considered for this position.

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