



Every year several patients and families from all around the world arrive at the SR-Tiget (San Raffaele Telethon Institute for Gene Therapy) in Milan for the gene therapy developed by the SR-Tiget researchers. The Fondazione Telethon **Just like home** program has been set up for these patients and families, **in order to support the access to the therapy for some rare diseases**. The gene therapy, include the approved drug for ADA-SCID (Strimvelis), as well as the trial treatments for disease such as Metachromatic Leukodystrophy, Wiskott-Aldrich Syndrome and Beta Thalassemia.

Supporting the family before, during and after their stay in Milan, the staff of the Program works to create **better conditions to access the therapy, contributing to the success of the therapy and avoiding negative emotional and logistical impact on the family life**. The therapy often involves a long journey, often from distant countries and a long stay in Milan, up to six months away from home as well as further periodical checks during the following years. The on-site support aims at ensuring that the family is set in a community that may emotionally and practically support the family during the stay and the treatment.



Specifically, the Fondazione Telethon staff will support families who come to Italy with a range of services:

● practical support

Families arriving at the SR-Tiget come from all over the world (till this day we have welcomed patients coming from more than 30 different countries). The so long journeys and the cultural differences, in some cases, prevent them from settling easily. The staff of the Program provides practical support before the journey to Milan, helping the parents to organize their journeys and finding accommodation for them. Fondazione Telethon may support – reviewed on a case by case basis – families to cover some expenses.

Psychological support

- Gene therapy implies that patient (very often a child) have to spend at least one and a half months inside a sterile room, while parents must alternate during the day to assist him/her. This situation can really put the most united families to the test, particularly those with other children and coming from far-off countries. Therefore the assistance of a psychologist who accompanies the various family members during treatment is an asset of the program. Professionals, like caregivers, professional educators or teachers, can also be involved in assisting

parents in following their children (inside and outside the sterile room) during the therapy.

Language support and cultural mediation

- Language is the main barrier for families coming to Milan. The Telethon staff collaborates closely with a team of language and cultural mediators able to welcome and guide the patient and parents during the phases of the therapy and within their new community.

A key figure: the care coordinator

- To offer all these services to families arriving in Milan, Fondazione Telethon provides a specific figure: the care coordinator that is a point of reference during the whole course of treatment (before, during and after therapy). The care coordinator works closely with a multidisciplinary team that includes psychologists, cultural mediators and, if necessary, professionals able to provide ad hoc services (e.g. teachers, caregivers, educators, etc.). While research nurses provide information on the therapy and its phases, the care coordinator provides assistance and information on travel, accommodation, services, logistical aspects, etc. The care coordinator also coordinates the network of volunteers who support families in their daily practical needs, sharing fears and joys, making them feel welcome, and never alone.



Caterina,
Care coordinator

«This job implies first of all to listen, and then to try and understand the needs of the families, expressed or unexpressed. We work on finding an answer to these needs, trying to involve the most suited people to help the families. Often it is me, in first person who solves the problems, but the thing that makes me happier is when I can give families the tools to handle difficult situations and I see them gain reassurance and overcome difficulties with a new force and with the knowledge of never being alone».

