

Gaza Strip: the untold Calvary of the “Butterfly Children”

“When my mother hugs me, I get blisters: unfortunately I am a butterfly child.” Ahmed is among over sixty Gazawi children suffering from epidermolysis bullosa (EB), a rare genetic disorder causing blisters and lesions of the skin and internal mucous membranes. They are called “butterfly children” because they cannot be touched or hugged - even touching them could cause hurt and pain. They spend most of their time at home. Children as fragile as butterfly wings. Their skin is so thin that a mere scratch is tantamount to a third or fourth degree burn. In most cases, their small hands are without nails, and in the most severe and invalidating stages, blistering lesions affect the joints of the hands and feet, making it very difficult for them to do anything.



The Butterfly Child syndrome is a non-transmissible condition without a cure, although various treatments, including gene therapy, are under investigation in clinical studies. Those affected require continuous care and attention, ranging from physiotherapy to special footwear, lotions, antibiotics and bandages to prevent cuts from coming into contact with clothing. The current medical approach to caring for these patients “is to avoid blisters by carefully protecting the skin and adopting appropriate lifestyles that limit trauma, and preventing secondary infections by meticulous treatment of wounds.”

At the forefront. The Palestinian enclave is ruled by Islamist movement Hamas since 2007 and is enclosed by the Israeli separation wall. The lives of its two million inhabitants are defined by continuing military conflicts with Israel - the latest past May - , and marked by a severe social and economic crisis, reflected in insufficient jobs, medicines, drinking water, electricity and essential goods. In this context, the Butterfly Children constitutes one of the many challenges faced by the Gazawi population. The Holy Family church, the only Latin (Catholic) parish in the Strip, with just over 100 faithful, is at the forefront of response and assistance to these sick children, assisted by Pro TS – Pro Terra Sancta, the NGO of the Custody of the Holy Land. Vincenzo Bellomo coordinates the project “Aid to the Butterfly Children.” He returned from the Gaza Strip just a few days ago, where he visited the families of the children assisted and reviewed the progress of the project, which has been running for a year and a half. “We are presently attending to the needs of 38 children”, he told SIR. Almost seventy children in the Strip are affected by the syndrome, at least those identified so far. Our project, which was launched at the end of 2020, builds on the efforts initiated a few years ago by some Italian volunteer doctors from PCRF-Italy, a non-profit organisation operating under the Palestinian NGO Palestine Children's Relief Fund (PCRF), dedicated to expanding the services and improving the quality of public health care in Palestine. The task of these Italian doctors was to provide home care and health and social support to the families of children suffering from epidermolysis bullosa in the Gaza Strip.” **Isahq and Sami.** “Aid to Butterfly Children” benefits from the contribution of Isahq, a young Muslim from Gaza. Isahq learned how to treat epidermolysis bullosa as a child because he himself suffers from it, albeit mildly. No one better than he can understand and help the young patients in their daily treatment,” Bellomo said. Every day, Isaac goes from house to house to bandage, apply skin preparations and clean the wounds on the skin of these children. He also explains to the family members of these young patients how they should be washed, treated and attended to, avoiding any additional suffering. The Palestinian health system

has not yet recognised this syndrome. It is being investigated by only a few doctors, and knowledge in this field is very scarce. When these children are taken to hospital, doctors think they have burns, when in fact it is epidermolysis bullosa. Bellomo recalled that "when a butterfly child was born, the doctors didn't know what to do, so they called our specialist, who arrived at the hospital in just a few hours and managed to separate the tiny fingers of the baby's hands, when the skin was not yet fully formed. Now this child is grown and undergoing palliative care. Since then, the family has been grateful to Isaac because they say he saved their daughter's life." Isahq is now being helped by Sami, a young Christian nursing student. The pandemic has made it necessary to scale up efforts and precautions. The majority of the young patients they look after are not yet vaccinated because of their age, and the rest of them have only received one dose. The two are supported by a small team of co-workers who handle all the paperwork related to treatment, administration and data collection. Bellomo pointed out: "It's extremely important to collect all relevant information on the disease, building on what has already been done by the PCRF doctors. It's a source of knowledge that must be enriched and shared. Moreover," Bellomo notes, "a book on this project has been written by Gianna Pasini, a nurse from Brescia and a volunteer with PCRF Italy."



Edizioni Q. It describes the life of a butterfly girl, amidst painful treatments, school classes and dreams to be fulfilled. Proceeds from the book go to the Pro TS project." **Children facing Calvary.** "There are countless practical difficulties," said Father Gabriel Romanelli, parish priest for the Gaza Strip.

But we must not abandon these children to a permanent calvary.

for that's what it amounts to: Calvary. We are working towards creating a facility that offers care and services to these children on a permanent basis, hence autonomous and independent. By helping these suffering children, we wish to offer a testimony of selfless love. *The wounds of these children, living throughout the Gaza Strip, remind us of their communion with the suffering of Christ and the five Holy Wounds that he endured painfully on Calvary. Let us heal their wounds for the good of all. As we approach Christmas, we are organizing a feast for them, and we hope that favourable conditions will permit it.* It will be an opportunity to give them presents such as skin creams and household appliances including fans, which are very useful in the summer heat to provide these children with some relief, since the hot temperatures cause their sores to worsen. We count very much on the generosity of many benefactors". To donate: <https://www.proterrasancta.org/en/take-action/#donaora> (reason for the donation: "Aiuto ai Bambini Farfalla" ("Aid to Butterfly Children") project.

Daniele Rocchi