

To the President of the Council of Ministers
Hon. Giorgia Meloni

and p.c.

Honourable Antonio Tajani
Vice President of the Council
Minister for Foreign Affairs and International Cooperation

Prefect Matteo Piantedosi
Interior Minister

Honourable Carlo Nordio
Minister of Justice

Prof. Orazio Schillaci
Minister of Health

Honourable Eugenia Maria Roccella
Minister for the family, birth rate and equal opportunities

Dr. Alessandra Locatelli
Minister for Disabilities

Most Illustrious Mr President,
Honourable Ministers,

following the case of the little Indi Gregory, an 8-month-old girl suffering from an incurable mitochondrial pathology, which reopened the important debate on the proportionality of treatment in the field of Paediatric Medicine, we would like to draw to your attention a series of reflections resulting from the experience acquired by the Maruzza Lefebvre D'Ovidio Foundation during many years working in the field of Palliative Care for infants, children and adolescents.

The case of little Indi generates a great deal of suffering in those directly involved and highlights, once again, the need for honest and competent reflection and debate, not only, in the medical community but also involving the general public. In the wake of the cases of Alfie Evans and Charlie Gard, in the motion of the 30th January 2020, the National Bioethics Committee expressed respected and directional guidelines for all those involved in the management of these extremely complex cases, which reiterated the need to avoid "*futile and painful clinical persistence and an unreasonable obstinacy of treatments in young children with limited life expectancies*".

TOGETHER FOR A BETTER TODAY.

While trust in medical and technological progress is undeniable, in the case of an incurable pathology, i.e. when the possibilities of survival are regrettably nil, it is dutiful and, more necessary than ever, to recognize their limitations.

Paediatric Palliative Care fosters a shift in focus of the treatment goals in serious illnesses by making available to the child patient and family all the care strategies necessary to live the best quality of life possible, without the unnecessary burden of technical devices and futile treatments.

Support for the child's parents and family members is fundamental throughout this dramatic journey: help to cope with their doubts by providing truthful answers to their questions based in medical science, acceptance of their frustration without making proposals that cannot reverse the course of the illness. Moreover, the proposal of miraculous solutions can become a new source of distress for other families with children with a similar diagnosis by arousing serious uncertainties about the medical treatment their child is receiving and by generating expectations that, inevitably, will be painfully dashed.

In the case of Indi Gregory, we believe that it was the wave of public emotion that played preeminent role in preventing a clear, albeit difficult, evaluation of the facts.

We are certain that this letter will receive your full attention.

Rome, 10 November 2023



Elvira Lefebvre D'Ovidio
President Maruzza Foundation